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ABSTRACT

The guide examines fundamental rights of mentally retarded and developmentally disabled persons. The monograph focuses on some of the central controversies of which consumers, professionals, planners, and advocates concerned with developmental disabilities should be aware. Problems of living and dying, resettlement and confinement, choice and coercion, assertion and passivity are considered. An overview chapter states the central problem in protecting human and legal rights, followed by a more in-depth look at specific court cases. Chapter 3 examines implications for the field of mental retardation of three major cases: Romeo v. Youngberg and the right to minimal training, Rogers v. Mills and the right to refuse treatment, and Rowley v. Hendrick Hudson Central School District and the right to appropriate education. Chapter 4 outlines methods to upgrade the quality of care, safeguard individual rights, and help consumers identify and exercise their rights. The final chapter summarizes themes and topics for further study, noting unsettled questions in such areas as equality, legitmacy, diversity, professionalism, and self determination. (CL)

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ISSUES IN HUMAN RIGHTS

A Guide for Parents, Professionals, Policymakers and All Those Who Are Concerned About the Rights of Mentally Retarded and Developmentally Disabled People

by

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PREFACE

The Young Adult Institute is publishing this monograph--"ISSUES IN HUMAN RIGHTS: A Guide for Parents, Professionals, Policymakers and All Those Who Are Concerned About the Rights of Mentally Retarded and Developmentally Disabled People"--because we care very deeply about all issues which affect the lives of the mentally retarded people we serve, their parents and other family members. We also believe that we have a professional responsibility to contribute to a better public understanding of the plight and predicament which confront all mentally disabled citizens.

In the penetrating and compassionate essay which follows, Professor Stanley Herr has brilliantly defined, analyzed and advocated for the legal rights of people with disabilities. Yet it should be understood that what we are talking about is more than legal rights. We are talking about basic human rights, including the right to lead dignified lives.

Indeed, as we approach the 21st century, the biggest challenge which confronts the mental retardation field is the struggle to secure human rights and dignity for the people we serve. This entails changing the public's attitudes and perceptions so that people with disabilities are no longer stigmatized. It means creating structures in society, as well as within our agencies, which encourage and facilitate the development and delivery of humane and dignified programs. Quite simply, it means treating people with disabilities in the same way that we ourselves would like to be treated. That is, with full appreciation of and consideration for their individual rights, abilities and potential.

The right to dignity, I would like to add, is dependent on the availability and provision of high quality programs and services. Take the case of Howard S., an orphan who spent most of his life in an institution; a life wasted by bureaucratic apathy and red tape. Howard came to the attention of the Young Adult Institute and was given a home in one of our residences. We worked hard with Howard, and Howard worked even harder. All he wanted was a chance: a chance to live without restrictions; to work and earn his own way in society.

Our professional staff taught Howard socialization skills, we provided him with prevocational training and, perhaps most important, we showed Howard that we believed in him. Our confidence in Howard was well founded. Recently

Howard moved into one of our satellite apartments. He now holds a competitive job, enjoys a dignified life, and is fully integrated into the community. And all he needed was a chance!

Unfortunately, however, there are thousands of Howards who are still waiting for their chance, who are still being deprived of their right to dignity, deprived of their human rights.

There are also thousands of individuals who have never been intitutionalized--who have always lived in the community--who are still being deprived of their human rights. It is ironic--and a sad commentary on our society--that those parents who have sacrificed all of their lives to keep their disabled family member at home, who have demonstrated courage and perseverance, who have saved the government millions of dollars, are being penalized for their fortitude.

Indeed, every day I am beseeched by parents and family members of mentally retarded individuals who plead for help. Parents often turn to the Young Adult Institute in time of crisis such as sudden death or a terrible illness in the family which makes it impossible for that family to continue to care for its mentally disabled loved one at home.

What does one say to a frail and elderly couple whose multiply handicapped daughter has "aged out" ("aging out" occurs when a mentally retarded or developmentally disabled person reaches the age of 21 and is no longer eligible for residential, educational and other child care services provided by the State) and has no place to go?

How do you respond to the pleas of a gallant and courageous mother who has struggled all her life to care for her mentally retarded son at home and now, afflicted with cancer, her final wish is to place her son in a community residence before she dies. Who will give her that peace of mind?

I confess that the most difficult part of my job is to tell such parents that there is simply no room for their child, and that it may take as long as three to five years for an opening to become available, if they are to find an opening at all.

As Professor Herr points out, there are people with needs and with rights out there, and it is up to all of us to see to it that these needs are fulfilled and that these rights are respected.

The Young Adult Institute, the Agency which I represent, firmly believes in the need to pass legislation which would protect, promote and perpetuate the rights of mentally retarded and developmentally disabled people, as well as their family members, to receive the services which they require.

We shall continue to fight for these rights, as well as for the rights of unserved and underserved populations such as the dually diagnosed, the multiply handicapped, the autistic, the mentally retarded offender, developmentally disabled members of minority groups, and mentally disabled people who are elderly. The plight of these people cries out for attention, and it is time that their rights too are respected.

Joel M. Levy, F.A.A.M.D.
Executive Director
Young Adult Institute

INTRODUCTION

This guide is about human rights and persons with disabilities. Under the Constitution and the United Nations Declaration of the Rights of Disabled Persons, it is now firmly established that mentally and physically disabled persons have fundamental rights equal to those of their more fortunately endowed fellow citizens. In the field of mental retardation, there is great interest in, but often hazy understanding of, the specific rights possessed by clients and the means of giving those rights effective implementation. This monograph is primarily intended as an aid to training and orientation activities dealing with the complex subject of the human and legal rights of clients in mental disability service systems. A secondary aim is to call further attention to rights developments with policy and programmatic implications.

These materials are, by design, introductory and highly selective. They stress problems of living and dying, resettlement and confinement, choice and coercion, assertion and passivity. They deal, for the most part, with the notorious rather than the mundane violation of human rights. These include some of the central controversies with which consumers, professionals, planners, and advocates concerned with developmental disabilities should be familiar. For related issues, documentation, and more comprehensive coverage, readers may wish to consult Rights and Advocacy for Retarded People (Lexington Books, 1983) or "Symposium on Mentally Retarded People and the Law" (Stanford Law Review, 1979).

Most service providers acknowledge that the protection of their clients' rights is one of their priorities and basic responsibilities. To put the point more strongly, the preservation of human rights is now an indispensable criterion for evaluating the calibre of human services. This remains true whether those programs are residential or daytime, public or private. Sound administration therefore requires identification of established rights and linkage to the means for their daily implementation.

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I. The General Problem: Protecting Human and Legal Rights

In response to a dismal history of neglect, discrimination and segregation, the friends and advocates of mentally retarded people undertook a variety of rights-related initiatives.

In a broad sense, rights are often classified as human, legal and civil. Human rights are claims on society for things that all people are entitled to have and enjoy. For example, some of those rights are defined in the U.N. Declaration on the Rights of Mentally Retarded Persons which stresses not only personal security against "exploitation, abuse and degrading treatment" but also rights to gain basic services with appropriate accomodations to individual differences. Legal rights are claims on particular persons or agencies for the enjoyment of rights which have been created by legislatures, courts, regulators, or parties to a contract. Administrative regulations, federal court decrees, and state and federal statutes, for instance, provide sources of detailed rules on the care and habilitation of mentally retarded persons. Civil rights are a category of basic legal rights that belong to persons by virtue of their citizenship in a state or country. Increasingly, persons with mental retardation have asserted such civil rights as the right to protection of the laws, voting, nondiscriminatory access to public services and accomodations, and other benefits of citizenship that an individual is qualified to exercise.

A. Who Guards the Guardians?

While the 1970s gave a sense of discovery of the enforceable legal rights of mentally retarded people, the 1980s heightened awareness of the huge tasks in making declared rights a reality. Even as this field resounds with the clash of litigation on an epic scale, work has begun on the long-term means of strengthening respect for clients' rights, such as the training of clients, staff, and human rights workers; the creation of new regultory frameworks; self-advocacy and self-governance; alternative means of complaint and dispute resolution for day-to-day issues; and the planning of environments that reinforce rather than conflict with the goals of normalization and human rights.

Massive denials of those rights and systemwide breakdowns in the provision of competent and compassionate care merited the time and cost of classwide remedies. Despite improvements in some states, persons with developmental disabilities urgently need additional ways to secure their rights. Some of the factors pointing to this need include:

- the demands for individualization of remedy
- speedy and thorough response to the unique grievances of the individual or the local group
- the desire for more flexible problem-solving in a nonadversarial atmosphere
- building and "internalizing" provider support for the promotion of practices that affirmatively support clients' rights.

B. From Repression to Rights

The history of mentally retarded persons in America reveals patterns of unequal treatment which frequently reflect traditional prejudices rather than legislative rationality. Policies of enforced segregation and eugenic sterilization on the basis of low intelligence at one time received wide support from lawmakers as well as professionals in this field. Martin Barr, an early president of the American Association on Mental Deficiency and an institutional superintendent, urged "asexualization" as "an effective means of race preservation," arguing for "the surgeon's knife in place of sentimentality."[1] The law was more preoccupied with protecting society from mentally retarded people than protecting mentally retarded people from society.

In the past twenty years, public opinion and legislative intent have dramatically shifted. This has led to judicial, legislative, and administrative awareness of the need for affirmative rights and safeguards to protect the human rights of people least able to protect themselves. The result is that the legal rights of persons with mental disabilities have geometrically expanded in recent years. Unfortunately, knowledge of those rights, attitudes, job descriptions, and practices have lagged far behind.

Law and advocacy can be a bulwark against drastic economies at the expense of the disabled. For example, when the federal Social Security Administration applied a more restrictive eligibility standard for deciding claims for Social Security Disability Insurance and Supplemental Security Income based upon a mental impairment, advocates went to court and won a ruling that the agency had failed to make the individualized determinations of ability to work required by statute.[2] Related lawsuits in federal courts have attacked the validity of federal benefit terminations when the notices mailed to mentally disabled clients were not likely to be understood or handled appropriately by such

clients, especially persons with limited reading skills.[3] These are but a few examples of the essential nature of class-action remedies for injuries that might otherwise be impossible to correct through repetitive individual actions.

The problem of ensuring some outside review of clients' complaints considerably predates these policy shifts or the activism of some judges. Complaint resolution procedures wholly internal to mental health departments have not inspired great confidence in the past. Writing in 1966 in the classic study, When Americans Complain,[4] Professor Walter Gellhorn observed that despite statutory mandates to protect mental patients' rights, patients had been shabbily treated for many years. Visits and inquiries by officials of New York State's Department of Mental Hygiene, had "failed to find the wrongs or to highlight the deficiencies that a later impartial study quickly disclosed." Routinization had eroded the value of these internal safeguards, for, as Professor Gellhorn concluded, "an administrator may cease to see and feel beyond the thickened walls of institutional custom until an outsider breaches them."[5] Although decisions by the Supreme Court and other federal and state courts helped to penetrate the old isolationism, equally important has been a change in approach by enlightened administrators, advocates, and the general public. This change is signaled by steps to ensure the basic rights of clients within the mental retardation delivery system through a fair, timely, and important grievance procedure. At a minimum, clients must be free to assert grievances or other rights without reprisal.

Devising and making such procedures work can unite clients, advocates, and responsible professionals. Self-advocacy groups can increasingly play a part in that process, providing that their members have been informed of their rights in understandable language and terms and have been offered the psychological support to stand up for their rights.

II. The Problem Narrowed: Enforcing Basic Rights

Some abuses are so widespread or deep-seated that conventional strategies of redress fail. Dehumanizing confinement in institutions and the withholding of essential medical care are two glaring examples. Because retarded people in general and handicapped children in particular have little or no political influence, they have historically suffered from such practices. In recent years, persons with handicaps, their families, and their friends have begun to demand legal rights and enforcement policies to avert these injustices. This section discusses four instances in which legal strategies have supplied a measure of political clout.

Today's political and economic environment places a premium on tenacious advocacy and disciplined case selection. Consent decrees are harder to obtain, and easier for the state to modify. Judges are more deferential to the judgments of qualified public professionals. Legislators are more cost-conscious. Federal regulators are increasingly conservative. Thus, effective advocacy may require multistage strategies, time-consuming appeals, cohesive coalitions, bargaining for incremental gains, and greater attentiveness to state policymaking. It also means choosing the "right issues" and being determined.

A. Aggregating Claims: The Pennhurst and Willowbrook Experiences

On January 23, 1984, the U.S. Supreme Court again ruled on the Pennhurst case. This marked the fourth year in a row that our highest court heard arguments on the rights of the residents of this Pennsylvania institution. Although they resolved the damage claim of Nicholas Romeo (Section III) the nine justices are split on the question of the legal basis for a federal court's power to order a deinstitutional remedy. In 1981, with three justices dissenting, the Court rejected the federal Developmentally Disabled Assistance and Bill of Rights Act as a source of that power.[6] In 1983, the justices failed to adjudicate the claim that federal courts, under the doctrine of pendent jurisdiction, may enforce a right to less-restrictive habilitation based on independent state law grounds. Instead, they ordered the parties to reargue that issue in the next Supreme Court term.

By a one vote margin, the Court rejected the federal courts' jurisdiction to issue injunctions against Pennhurst and state officials on the basis of state law. In a technical and highly controversial opinion, the majority held that considerations of federalism and sovereign immunity

under the Eleventh Amendment bar federal courts from requiring state officials to conform their conduct to state law where the claim is aimed against the state (No. 81-2101). Justice Stevens, in a bitter dissent, criticized this ruling as overturning well-established doctrines and precedents, violating the Supreme Court's own rule of avoiding constitutional decisions when a case can be decided on a statutory basis, and unjustifiably prolonging the Pennhurst litigation. Thus, this ten year case goes on. The lower courts now face a third round of litigation in which Pennhurst residents can raise claims under constitutional due process and equal protection, Section 504 (the antidiscrimination provisions of the Federal Rehabilitation Act), and the Developmentally Disabled Assistance and Bill of Rights Act (42 U.S.C. 6011, 6063).

But regardless of the legal outcome at this stage, the population of Pennhurst will continue to decrease. By June 1984 state officials plan to decrease that population to 393 persons, and by June 1985 to 212 persons. Thus, whatever the courts ultimately decide, a Pennhurst of some 200 people could become too expensive and too cost-ineffective for the state to operate. The plaintiffs could well declare a victory because the closure of Pennhurst is only a matter of time.

Halderman v. Pennhurst State School and Hospital began as an avowedly anti-institutional case. It was intended to demonstrate that the institution could not provide proper habilitation, and that the continued existence of even an upgraded Pennhurst would constitute an illegal denial of its residents' right to habilitation.* The district court agreed and declared that segregation in Pennhurst violated constitutional and statutory rights to nondiscriminatory habilitation and to minimally adequate habilitation. Remedying these violations would require plans, processes, and resources to assure class plaintiffs (Pennhurst residents and retarded persons at risk of such institutionalization) of the least separate, most integrated, least restrictive community settings. Steps to improve conditions in the institution were simply interim measures until all the residents could be moved to normalizing environments.

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* Habilitation refers to the process of educating, training, and caring for the individual in order to improve his or her development and ability to cope with the demands of the environment.

Shifts in legal doctrine led to an enforcement strategy emphasizing individual habilitation plans. By declining to uphold a total prohibition on the use of Pennhurst, the U.S. Court of Appeals for the Third Circuit relegated the plaintiffs to individual determinations by the trial judge or special master as to what would constitute the least restrictive setting appropriate to a particular client's needs. In response, professionals have designed individual habilitation plans with a strong presumption in favor of deinstitutionalization. This, in turn, has required an advocacy system to represent class members who had no parents or close relatives,[7] and repeated interventions by the trial judge to clear roadblocks to placements in approved community facilities.[8]

Although political resistance has slowed the pace of community placement, the Pennhurst case offers convincing proof that retarded people and their friends can change destructive service patterns. At the original trial in 1977, state officials had affirmed their belief in community alternatives and the state's intention to close Pennhurst in the early 1980s. Yet, as the orders of Judge Broderick have recently made clear, the defendants have not met specific placement deadlines and the state has not funded the county proposals that could speed the phasing-out of Pennhurst. More surprisingly, the state has failed to take full advantage of such federal aid programs as Title XIX and the Medicaid waiver that could "drastically reduce the Commonwealth's cost of community placement of the mentally retarded."[9] Despite these impediments, the institution's population has dropped to two-thirds of the 1,944 individuals residing there when the lawsuit began. For those ex-residents now in community living arrangements, progress has been tangible, dramatic, and well-documented.

As the Willowbrook case enters its second decade, the end is still far from sight. In 1969, this Staten Island institution was overfilled with 6,200 residents. Once the world's largest (and perhaps most infamous) retardation facility, this "Developmental Center" now houses some 1,300 residents. A consent judgment approved in 1975 calls for a reduction to no more than 250 beds. Although this aspect of the decree was to have been achieved by April 1981, the court has extended this deadline to April 1985. At stake is more than the fate of the remaining residents and staff or the credibility of judicially enforced mandates for the rights of retarded people. Symbolically and practically, this litigation marks the transition from institution-centered to community-centered care.[10]

Emptying Willowbrook has become the overriding objective of the case best known as New York State Association for Retarded Children v. Carey.[11] By April 1982, the failure of state attempts to improve conditions within the institution had been conclusively proved. Judge Bartels' graphic findings of noncompliance with consent judgment standards of sanitation, clothing, programming, and other living conditions were readily upheld by the Court of Appeals. But the Second Circuit insisted that the bed limitation in defining community placement be relaxed where adherence to the consent judgment's 15-bed and 10-bed restriction would slow the movement of class members from Willowbrook's "squalid living conditions" to facilities of "more human dimension."[12] Beyond this preference for speedier, if only partial relief, the appellate judges rely on two legal reasons:

> First, a more generous standard for modification of consent decrees in institutional reform litigation if the remedy is not working effectively or is unnecessarily burdensome to the achievement of its main object.
>
> Second, a constraint on the district judge's freely choosing between divided expert opinions when the defendant's experts may have been within the Youngberg v. Romeo zone of "accepted professional judgment." (For discussion of that case and standard, and its questionable application to an injunctive remedy of this type, see pages 19-24. infra)

A special master has been appointed to fill the gap left by the defunding of the Willowbrook Review Panel. On July 13, 1982, Judge Bartels named Dr. Rudy Magnone as special master and directed him to monitor and facilitate implementation of the judgment. Although many of his powers and duties are patterned after the Willowbrook Review Panel, the master is likely to operate in a less formal manner than the panel in realizing the community placement goals. By design and by law, this job is not that of gladiator or de facto administrator.

"Fixing up Willowbrook is like attaching a heart-and-lung machine to a cadaver." Ten years ago, an expert witness for the defendants voiced these doubts over state plans to rehabilitate this institution. If that warning had been heeded, millions of dollars and the human rights of countless residents could have been saved.

In his 1984 State of the State Message, Governor Cuomo has acknowledged this costly lesson, pledging to close Willowbrook and to replace it with small community residences. "Its closing," he explained, "will symbolize our resolve to give the disabled the dignity and independence that is their right." Other states should form similar resolves in remedying their own institutional quagmires.

B. Saving Lives: The Lessons of Baby Doe and Phillip Becker

Unlike the glaring problem of institutions, the denial of essential medical treatment to handicapped children poses the problem of making invisible injustices visible. No one knows exactly how many infants and children have lost their lives or had their handicaps aggravated by a discriminatory denial of food or potentially beneficial treatment. Wolf Wolfensberger suggests that the deaths of unwanted persons of various ages are "so disguised that most people are not conscious of them," estimating that 200,000 "afflicted people" have their lives taken every year.[13] Since the withholding decision for a handicapped child is usually made by the parents and ratified by a doctor, doubtful decisions are shrouded in a conspiracy of silence. Baby Doe and Phillip Becker--both Down's syndrome children--are rare cases breaking that silence.

The short life of Bloomington's Baby Doe has sparked a long and heated controversy. In April 1982, this Indiana baby with Down's syndrome died at the age of six days because his parents refused surgery to correct a birth defect which prevented food from reaching the baby's stomach. The state courts refused to intervene and the baby died before a guardian ad litem could petition the U.S. Supreme Court to reverse that decision. These traumatic events recalled the starvation and death of the so-called Johns Hopkins baby under similar circumstances. Thus, infants with Down's syndrome continue to be at special risk of "pediatric euthanasia," a risk heightened by misinformation as to the capabilities of such children and by advice motivated not by the "desire to prevent pain and suffering" but by desires to "rid society of what are considered useless lives."[14]

With this background in mind, the Association for Retarded Citizens, the American Association on Mental Deficiency, the President's Committee on Mental Retardation, and President Reagan were quick to condemn the death of Baby Doe.

The federal response was a rush to regulate. A month after Baby Doe's death, the Secretary of Health and Human Services (HHS) issued a notice to hospitals that the anti-

discrimination provisions of Section 504 of the Rehabilitation Act applied to such situations and made unlawful the withholding of nutrition, surgery, or medical treatment if required to correct a life-threatening condition. Health care providers were advised that failure to comply with Section 504 could lead to termination of federal assistance. Ten months later, HHS issued a regulation requiring medical institutions receiving such assistance to post a notice that the "discriminatory failure to feed and care for handicapped infants...is prohibited by federal law." The notice urged that anyone having knowledge of such discrimination should contact a federal hotline or a state child protective agency. The regulation also authorized HHS civil rights investigators to protect the life or health of a handicapped infant, and to have immediate access to hospital records and facilities in pursuing such investigations. Two weeks after this regulation was published it became effective as an interim final rule. Despite the normal requirements of the Administrative Procedure Act (APA), no public notice or opportunity for consultation with affected parties was provided.

Judge Gerhard Gesell's opinion of April 1983 invalidates the "Baby Doe" regulation and casts doubts on its hotline approach. It holds that Secretary Heckler's failure to follow the APA procedural requirements for public participation in rulemaking and her "arbitrary and capricious" failure to consider relevant factors render the interim final rule of no further force. In striking down this rule, the district court relies on the HHS failure to comply with the 30-day notice and comment requirements under circumstances which do not satisfy the emergency exception. But the judge's critique of the department's hasty and inexperienced decision-making and of the supposed intrusive effects of the "sudden descent of 'Baby Doe' squads on the scene" goes much further. In American Academy of Pediatrics v. Heckler, he recites a host of factors which the Secretary may not have adequately considered: the motivations of "anonymous tipsters," burdens on medical staff, the prospect of children being removed from hospitals, intrusion into family autonomy, and the lack of clear medical and legal standards to guide care providers.[15] Without deciding the matters, the court observes that the challenged regulation raises statutory and consitutional questions of the Secretary's authority to use Section 504 for this purpose and to intervene in the "difficult and sensitive situations where life may hang in the balance."[16]

As regulators and child care advocates return to their drawing boards, they should ponder the spectrum of enforcement strategies. There is some reason to doubt not only the

wisdom but also the effectiveness of hotlines to disclose valid complaints. During the month in which the "Handicapped Infant Hotline" operated, 600 calls were received, but only 16 involved a specific allegation, of which five merited investigation. None have so far warranted further action.[17] Learning from this experience, regulators could attempt to define more clearly the rules and the processes for uncovering their violation. The rules need not be inflexibly detailed and could be based on such principles as the primacy of the child's best interests or the illegality of withholding food and essential treatment on grounds of mental retardation. Furthermore, Congress or state legislatures could clarify the responsibilities of care providers and the child's surrogates. Indeed, a flurry of legislative proposals seek just that end.[18] Hospitals need not wait for outside direction, but can devise their own internal protocols, and submit to human rights committee reviews in doubtful cases. Clinicians and advocates should collaborate to strengthen their counseling, positive incentives, and intervention procedures that will advance the best interests of infants as well as older children with medically treatable handicaps.

A new "Baby Doe" rule, effective February 13, 1984, should also help ensure adequate protection of, and representation for handicapped infants. It requires the posting of an informational notice that under federal law nourishment and medically beneficial treatment should not be withheld from handicapped infants solely on the basis of mental or physical impairments. It requires state child protective service agencies to establish procedures to use their full authority under state laws to prevent unlawful medical neglect of handicapped infants. On a voluntary basis, health care providers are also encouraged to create Infant Care Review Committees to develop standards, policies, and procedures in making decisions in specific cases. For example, one of the Committee's members could be designated to act as a "special advocate" for the infant to "ensure that all considerations in favor of the provision of life-sustaining treatment" are considered by the Committee. These regulations carefully balance the legitimate interests of parents and health care providers with the child's interest in receiving timely and medically beneficial treatment.

The widely publicized case of Phillip Becker is a fearful reminder of who bears the costs of delay when those interests are not implemented. Within days of his birth, this Down's syndrome child was transferred from a hospital nursery to an institution. Although Phillip's parents were first notified of his ventricular spetal defect ("hole-in-

the-heart") when he was three years old, they repeatedly refused to consent to corrective surgery. Left untreated, this progressive form of pulmonary vascular disease could cause a slow and painful death. Despite this dire medical prognosis and vivid warnings that Phillip would face a "bed-to-chair existence, "coughing up blood," and "great suffering," the Beckers rejected medical help for Phillip when he was six and again at age eleven. According to their own testimony at trial, their decision was motivated by Phillip's mental retardation and their fears that with surgery he might outlive them. As Mr. Becker admitted, "If my other two (non-retarded) boys had the same problem, they could have the operation."[19]

The state authorities viewed the Phillip's plight in a too-narrow context of parental neglect and medical detriment. In April 1978, the California district attorney petitioned the juvenile court to determine that the Beckers' decision to deny surgery constituted neglect under state law and to approve heart surgery. This proceeding lasted less than two days, did not raise any other denials of Phillip's rights (such as education and habilitation), and would not have changed the Becker's custodial arrangements for him. The juvenile court dismissed the petition on the grounds that the state had not met its burden of proof, and the court of appeal affirmed because it could not say "as a matter of law that there was no substnaitl evidence to support the decision of the trial court."[20] But the de facto parents of Phillip, Herb and Patsy Heath, were never asked to testify in those proceedings and the substantial evidence that could have tipped the balance in favor of the child's best interests was not marshalled in 1978.

The California courts have, at long last, properly upheld Phillip's right to a decision-maker committed to his best interests. In August 1981, based upon a twelve-day trial, a superior court awarded guardianship to the Heaths and authorized them to have a heart catheterization performed immediately to assess the current risks of surgery. As a result, Phillip was able to leave a board-and-care facility, to live in the Heath's home, and to enjoy a more normal life. Phillip has now lived in that home since September 1981. But the Beckers continued to block the catheterization and stayed that order pending appeal.

On January 23, 1983, the California Court of Appeal dismissed the Beckers' appeal and the California Supreme Court has since denied their petition for a hearing. The Court of Appeal held that the award of guardianship and custody was fully justified under state law. Their unanimous

opinion pointed out that the record abundantly demonstrated that the Beckers' continued custody would cause Phillip "profound emotional harm," "educational and developmental injury," and "potential physical harm" due to their passive neglect of his medical needs. This decision simply applies established legal principles to the unique facts and detriments experienced by Phillip. The legal victory has finally produced the long-desired outcomes: successful surgery to repair the heart defect; Phillip's rapid recovery to a vigorous lifestyle; and the prospects of full membership in a loving family.

A child with developmental disabilities should be entitled to a mended environment as well as a mended heart. As the appellate court emphasized, California law declares that such persons have the rights to treatment and rehabilitation services, publicly supported education, social interaction, and prompt medical care and treatment. Idosyncratic personal judgments which devalue the lives of disabled persons cannot be allowed to override the child's paramount interests and these strong legislative policies. Yet battles against such bias, all too sadly, are bound to reoccur.

III. Implications of Recent Supreme Court Decisions

The 1981 Supreme Court term marked a watershed in mental disability law. For the first time in its history, the Court considered the substantive rights of involuntarily committed mentally retarded persons. For the first time, the justices also confronted the difficult questions surrounding the right to refuse treatment. Again for the first time, our highest court construed the language of a far-reaching federal law: the Education for All Handicapped Children Act (P.L. 94-142). These milestone decisions alone would have generated the widest interest from administrators, clinicians, direct-care employes, advocates, consumers, and their friends. But there was even more: the granting of certiorari, the Court's discretionary power to hear a case, for yet another round of Supreme Court review of the Pennhurst State School case; the upholding of a consumer's standing to sue for alleged conspiracies to deter the use of psychologists under Blue Cross plans; and the affirmation of the rights of civil-rights suit plaintiffs to obtain judicial remedies without first exhausting administrative remedies. The mental retardation field will be digesting the import of all these remarkable decisions for years to come. The following section summarizes three of the most significant High Court decisions.

A. Impact on the Mental Retardation Field

There are many different ways of reading Supreme Court decisions. At one level, lawyers search them out for the "holdings," the narrow conclusion or conclusions reached by the Court in settling the question of law raised by that particular case. Other parts of the justices' analysis which are unnecessary to settling that question are referred to as "dicta." For that reason, such views are not binding upon the lower courts. While the majority opinion constitutes the precedent of the case, concurring and even dissenting opinions often influence the future development of the law.

With change in the Court's personnel, and new insights into legal knowledge and habilitation practice, today's dissent can form the foundation for tomorrow's majority holding. Because case law is incremental and builds upon the specific disputes by the parties, it is often difficult to predict judicial trends. Beyond the technical cannons of legal analysis, there are other meanings to be drawn from Supreme Court opinions.

1. Symbols for Society

In ringing terms, courts can clarify the value system embedded in the Constitution and honored in American principles, if not practices. Brown v. Board of Education, outlawing racially segregated schooling, is the classic example. Women, aliens, illegitimate children, and other disfavored groups have also challenged stereotypes and legally imposed stigmas through the courts. Similarly, persons with mental disabilities continue to press claims upon the courts which can alter their place in, and acceptance by, American communities. A by-product of these efforts is to announce and confirm new expectations, new treatment models, and new roles for developmentally disabled persons in our society.

2. Signals to Professionals and Administrators

Supreme Court decisions, especially those involving money damages, transmit powerful messages as to what constitutes professionally and socially unacceptable treatment (or nontreatment) practices. Rigid or unrealistic standards can have a chilling effect on professional recruitment, the exercise of reasonable discretion, or the willingness of staff to assume professional responsibility. This Supreme Court, sensitive to these considerations, recently stated that "the administrators, and particularly professional personnel, should not be required to make each decision in the shadow of an action for damages."[21] Other types of actions, such as those for injunctions and declaratory relief, can also generate appropriate standards, endorse habilitation principles, and elicit new sources of public support.

3. Sources of Training on Clients' Rights

Under Medicaid regulations for intermediate care facilities for the mentally retarded (ICF-MRs) and under the law of many states, service providers have duties to inform and train persons in the exercise of clients' rights. For example, according to 104 Code of Massachusetts Regulations Section 20.14 (1) (b)5., human rights committees are authorized to "review and monitor the means used by the program" to "inform clients, staff, guardians, and families of the clients' rights" and the means used to "train persons served by the program in the exercise of their rights." More directly, human rights officers, acting under the committee's general directions and with the Department of Mental Health's technical assistance, have the duty to "develop and implement means" to inform the designated audiences of clients' rights, to train persons served by the progam in the exercise of

their rights, to inform them of "the grievance procedures," and otherwise to assist the program in promoting the human and civil rights of clients.[22]

Given the multitude of rights that clients possess as ordinary citizens and as consumers of generic and specialized publicly provided services, human rights committees and officers cannot possibly cover all the local, state, and federal sources of relevant rights. But neither can they ignore these training and information responsibilities. The rights interpreted by recent United States Supreme Court decisions are certainly useful and important starting points for the work of these officers and human rights committees.

B. Romeo v. Youngberg and the Right to Minimally Adequate Training

On June 18, 1982, the Supreme Court of the United States unanimously upheld the right of Nicholas Romeo, a profoundly retarded man, to sue three administrators of a state mental retardation institution for damages for a violation of his constitutional right to care and habilitation training. Acting through his mother and legally designated "next friend," Paula Romeo, he claimed that repeated pnysical injuries, unreasonably bodily restraints, and insufficient training had violated his constitutional rights to substantive due process under the Fourteenth Amendment. In essence, the Supreme Court agreed with Romeo's poignant complaint. remanding the case for further proceedings, thus clearing the way for a new jury trial with new legal instructions. To understand some of the nuances of this ruling requires a brief case history, as well as a summary and commentary on the Supreme Court's action.

1. Romeo's Themes

Two major themes echo throughout Romeo's litigation. First, mentally retarded persons, innocent of any crime, deserve greater constitutional consideration then convicted felons. Second, in determining what constitutes a violation of the constitutional rights of confined retarded persons, courts should act with due deference to qualified professionals acting within the realm of accepted professional practices and standards. But underlying these broad themes is a discordant debate: should the courts, in effect, offer a guide to retarded residents' rights for the purposes of settling a wide array of future disputes? Or should they adhere to a more cautious common law tradition of avoiding advisory opinions and the risks of developing legal rules

without the concrete evidence drawn from the crucible of fully litigated controversies? The Supreme Court's opinion squarely endorses the latter, more traditional, approach.

2. The Issues at Trial

In April 1978, the United States District Court for the Eastern District of Pennsylvania held an eight-day jury trial on Romeo's complaint. His core allegations were as follows:

- Over a period of two years, the plaintiff had "suffered injuries on at least sixty-three occasions" through self-injurious behavior and attacks by other residents
- The Pennhurst director and two supervisors, the Director of Resident Life and the Unit Director, knew, or should have known, that Romeo was suffering these injuries
- They failed to adopt appropriate preventive procedures, thus violating his rights under the Eighth (ban on "cruel and unusual punishment") and Fourteenth Amendments (no taking of a person's "life, liberty, or property, without due process of law....")
- Failure to provide Romeo with appropriate "treatment or programs for his mental retardation" was compensable by damages

The portrait of Romeo emerging from trial is a despairing one. Until age 26 and his father's death, he lived with his parents in their Philadelphia home. With his mother unable to handle and care for him unaided, he was involuntarily committed to Pennhurst. There his aggressive behavior led to a devastating array of injuries to his arm, fingers, sexual organs, eyes, and skin. Some of these injuries became infected, either from inadequate medical attention or from contact with human excrement.

Labeled profoundly retarded, lacking speech and rudimentary self-care skills, Romeo was confined to the Pennhurst infirmary, his world further constricted by the physical restraints on his arms. At the time of his trial, there was evidence of some programming for self-care skills. However, a behavior modification program to reduce Romeo's aggressive behavior, rejected by his mother, was never implemented. In the infirmary, there were apparently even fewer habilitation programs. But the judge barred two professionals--Romeo's

expert witnesses--from testifying as to the impact of this lack of programming, alternative methods of treatment, and the improper use of restraints for the convenience of staff.

Ultimately, this error of law, and the judge's jury instructions would require a new trial. Adopting a standard used in prisoners' Eighth Amendment cases, the trial judge instructed the jury to uphold Romeo's Eighth and Fourteenth Amendment rights only if they found the defendants "deliberately indifferent" to the serious medical and psychological needs of the plaintiff. Other instructions permitted the jury to find violations of constitutional rights "if any or all of the defendants were aware of and failed to take reasonable steps to prevent repeated attacks upon Nicholas Romeo," or if the defendants shackled Romeo or denied him treatment as a punishment for filing the lawsuit. Upon these instructions, and lacking the judicially excluded evidence, the jury found in favor of the defendant administrators.

3. The Appellate Holdings

The stage was set for appellate reversal and a groundbreaking opinion in post-commitment law. The federal Court of Appeals for the Third Circuit, with all of its members participating, reversed the lower court decision and remanded the case for a new trial. In doing so, they held that liberty interests under the Fourteenth Amendment protect a right to freedom from undue bodily restraint, a right to personal security, and a right to treatment or habilitation.

Circuit Judge Adams, writing for the majority, conceded that this controversy "inhabits the twilight area of developing law concerning the constitutional rights of the involuntarily committed mentally retarded." Yet the Third Circuit, covering Pennsylvania and New Jersey, had not hesitated before in entering other grey areas of law: the various stages of the Pennhurst deinstitutionalization case; the search for constitutionally appropriate commitment standards for youngsters in Bartley and Institutionalized Juveniles, or Rennie's struggle to resist psychoactive drugs.[23]

The opinion of the Third Circuit squarely upheld the constitutional right to treatment, usually referred to as the right to habilitation in the case of mentally retarded persons. The Fourteenth Amendment, rather than the Eighth Amendment (protecting those convicted of crimes from cruel punishment), was held to be the source of constitutional rights for involuntarily committed mentally retarded persons. The court recognized habilitation as involving a "developmental view," referring to the capacities of even severely

retarded persons to improve, learn, and grow. The Court of Appeals noted that fewer retarded persons, in contrast to persons treated for mental illness, are "totally untreatable" or beyond the help of "effective therapy." Furthermore, the full court had no difficulty in holding that committed retarded persons retain Fourteenth Amendment liberty interests in freedom of movement and in personal security, even within an institution. Thus, a new trial was ordered.

The appellate court divided, however, on the standards to be applied in determining infringements of these rights. The six-judge majority ruled that the jury should be instructed that Romeo should win if he "did not receive a form of treatment that is regarded as acceptable for him in light of present medical or other scientific knowledge." But the defendants were entitled to a "qualified immunity defense" instruction, and to introduce evidence of security, administrative, and fiscal constraints in order to avoid liability. In a complex array of rulings and dicta, the majority outlined proofs of "compelling necessity" for physical restraints, "substantial necessity" for failure to take steps protective of personal security, and appropriate balances to be struck in weighing claims of no treatment, intrusive treatment, and inadequate treatment.

Chief Judge Seitz, concurring in the judgment, also affirmed the retarded person's "constitutional right to minimally adequate care and treatment." Indeed, his use of the term "treatment" is synonymous with training or habilitation. His view, ultimately adopted by the United States Supreme Court, urged a simplified and less stringent standard: whether the defendants' conduct was such a "substantial departure from accepted professional judgment, practice or standards as to demonstrate that the defendants did not base their conduct on a professional judgment." This will be referred to again as the professional judgment test since deference to such judgment is placed at the core of future constitutional damage actions. Higher standards may apply in other types of lawsuits (see page 22).

Two other judges were critical of the majority's sweeping opinion and its potential for confusing juries and confounding habilitation professionals. Judge Aldisert's spirited views show considerable sympathy for those working in the mental retardation field during this period of legal change:

> It has been almost twenty years since I faced a client across a law office desk. But were I to be placed in that position

> today, my advice would probably go like this: if you are contemplating a position as an attendant in a mental hospital, seek another job: there is simply too much unpredictability in the law governing your conduct. If you are a physician, make certain that the state's malpractice insurance policy includes a clause protecting you from the new "constitutional torts" manufactured today by the Third Circuit Court of Appeals.

4. The Supreme Court Ruling

The High Court's judgment is a remarkable feat: A highly controversial case commanding a unanimous vote. What explains this generally conservative Court putting its seal of approval on a right to "minimally adequate treatment"? Part of the answer lies in the compromise embodied in the opinion: recognition of a narrow right tailored to the plaintiff's asserted wrong in exchange for a standard of liability relying on the "presumption of correctness" of qualified professional judgment. While the constitutional holding goes far beyond the Court's 1975 Donaldson[24] result, there is an echo of the Donaldson method in this carefully crafted opinion.

Like Donaldson, the Romeo Court avoids sweeping questions in favor of narrower resolutions. Their opinion suggests constitutional litigation developing through incremental stages, rather than in bold advances. They resoundingly endorse the rights of retarded persons, but also recognize the practical difficulties confronting workers in the mental retardation field. In the questions left open, there is both an encouragement to further judicial tests and disapproval of judicial intrusion.

For purpose of legal analysis, the Romeo opinon can be separated into three sets of legal rights:

> Those conceded by the state;
> those disputed by the parties;
> those reserved for future decision by the Court.

The state conceded that the respondent, involuntarily committed to a state institution for the mentally retarded, has a right to adequate food, shelter, clothing, and medical care. The Supreme Court confirms these as "the essentials of the care that the state must provide."[25] Thus, a relatively broad constitutional right to care is not disputed.

Nor does the Supreme Court have any difficulty in deciding questions relating to safe custody and freedom of movement. In rapid order, the Justices hold that traditional liberty interests in personal security and freedom of movement extend to mentally retarded persons. Thus, persons like Romeo are entitled to substantive protection under the due process clause. These constitutional rights survive even a person's commitment to a mental retardation facility. Reasoning by analogy, Justice Powell writes: "If it is cruel and unusual punishment to hold convicted criminals in unsafe conditions, it must be unconstitutional to confine the involuntarily committed--who may not be punished at all--in unsafe conditions."

The constitutional right to minimally adequate habilitation is more troubling to this Court. Its opinion reveals uncertainty as to the exact definition, scope and manner of enforceability of this right. Nonetheless, the Supreme Court, relying on the formulations of Chief Judge Seitz, held that Romeo is constitutionally entitled to "minimally adequate or reasonable training to ensure safety and freedom from undue restraint." On remand and through future cases, this right can be more precisely defined on a case-by-case analysis of the facts and circumstances of the individual's confinement. Thus, disputes as to the adequacy of training can be properly decided by a court, and courts are instructed to "start with the generalization that there is a right to minimally adequate training."[26] By reading Romeo's requests for treatment as primarily aimed at reducing restraints and aggressive behavior, and providing training in self-care skills, the Supreme Court avoided determination of broader issues. According to the Court, the State must provide Romeo with training that "an appropriate professional would consider reasonable to ensure his safety and to facilitate his ability to function free from bodily restraints."

By what criteria will Romeo-type complaints be decided? Here the Court refers to familiar balancing tests since the rights articulated are not absolute. Restraints, for example, may sometimes be required to protect an individual from violence or to permit training to take place. Stated most broadly, "whether respondent's constitutional rights have been violated must be determined by balancing his liberty interests against the relevant state interests."

But the Court's standards are more specific, although not without ambiguities. They rest midway between the liability test designed for criminal confinement and the Third Circuit's more searching "compelling" or "substantial" necessity tests. "In this case, the minimally adequate

training required by the Constitution is such training as may be reasonable in light of respondent's liberty interests in safety and freedom from unreasonable restraints."[27] In essence, liability should not be assessed on the basis of mere differences of professional opinion nor on departures from a clinician's "normal professional standards because of budgetary constraints." With considerable emphasis on the deference due to the "judgment exercised by a qualified professional," the Court adopts what it calls a "presumption of correctness," concluding that: "liability may be imposed only when the decision by the professional is such a substantial departure from accepted professional judgment, practice or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment."[28]

Simply because the Romeo case has staked out certain constitutionally protected interests does not mean that reasonable professionals, administrators and direct care workers can ignore other rights and interests. In summary, the Court has upheld rights to "conditions of reasonable care and safety, reasonably non-restrictive confinement conditions, and such training as may be required by these interests." But the Court's members leave open a potpourri of legal questions with only hints at the ultimate answers in an appropriate future case. A few of the questions reserved for the future include:

- Whether a mentally retarded person, involuntarily committed to a state institution, has some general constitutional rights to training per se.
- Whether the extent and nature of the treatment obligation varies with the resident's prospects for freedom or other institutional release.
- Whether a state statutory right to habilitation is entitled to substantive protection under federal due process constitutional law.
- Whether a total denial of the treatment promised under state law is unconstitutional.
- Whether a state's unreasonable refusal to provide training to preserve the resident's self-care skills (i.e., the life skill he or she possessed at the time of entering state custody) is unconstitutional.

- Whether the state is under an affirmative constitutional duty to assist residents to acquire new skills that will enable them to realize their potential to live outside the institution (with the help of relatives, friends, or in other less restrictive living arrangements).

These are only some of the difficult questions, expressed or implied, that remain unsettled. Youngberg v. Romeo marks only the end of the beginning of a long struggle for the rights of mentally retarded people.

5. Implications for Clients' Rights and Staff Training

It is critical to note that federal constitutional law represents only the most minimal requirements of law. The Supreme Court's affirmative decision for Nicholas Romeo in no way precludes, or otherwise limits, higher standards of care and habilitation that state statutes and regulations, federal statutes and regulations, and consent decrees may require. Plainly, the Romeo rules are only supplements to the regulations and accreditation standards governing day-to-day situations. For instance, state malpractice actions, based upon standards of care employed by a reasonable expert or majority of experts in the community, pose a different and more stringent test.

Yet Youngberg v. Romeo will have influences on clients' rights that exceed its doctrinal impact. It is a breakthrough in the Supreme Court's recognition of the basic rights of institutionalized persons with mental retardation. As such, it puts to rest any lingering doubts as to the legitimacy and enforceability of such rights. Since it is a precedent involving a profoundly retarded man with limited functional abilities, it makes clear that even the most disabled individual is entitled to some form of training. Courts are extremely cautious in marking new areas for damage liability, therefore we can expect more generous--or at least different--measures of injunctive relief for constitutional rights to training or habilitation. (An injunction is a type of court order that forbids or commands a party to do some particular act). This is not to say that the exact contours of clients' rights can be accurately predicted in future cases. Because Romeo's parent and counsel, according to Justice Powell, specifically disavowed any request for institutional release, the Court did not reach the question of the least restrictive alternative living arrangement. Since Romeo had been committed through involuntary pro-

cedures, the rights of those committed through other processes may vary in some respects. Although its references are cryptic, the Supreme Court's opinion at certain points commands equality of treatment for all residents: "The state also has the unquestioned duty to provide reasonable safety for all residents and personnel within the institution." Thus the various duties articulated in Romeo clearly require consideration and concern for each resident's rights, not only for those, like Romeo, who exhibit bizarre and/or aggressive behaviors.

The Romeo case is thus an important impetus to staff training and orientation on residents' rights. Most immediately, it will spur inquiry into what constitutes "reasonable" care and safety conditions, "reasonably" nonrestrictive confinement conditions, and "reasonable" training programs to reduce a resident's need for restraints or the likelihood of violence. Much of the responsibility for making such determinations will ultimately fall on the qualified professional decisionmaker. For this and other reasons, employees without formal courses of training are not likely to be targets of legal liability, especially when they are acting under the supervision and direction of qualified persons. Yet, those direct-care staff who make day-to-day decisions clearly need and deserve guidance as to the spheres of decisionmaking in which they can operate on their own initiative, and as to those extraordinary treatments or restraints which require a supervisory professional's review and approval.

The Supreme Court's opinion shows keen awareness of these levels of decisionmaking. Romeo accords special deference to the habilitation professional who must function in retardation institutions, facilities which the Court acknowledges are "often, unfortunately, overcrowded and understaffed." Accordingly, the Supreme Court broadly defines a professional decisionmaker as:

> ... a person competent, whether by education, training or experience, to make the particular decision at issue. Long term treatment decisions normally should be made by persons with degrees in medicine or nursing, or with appropriate training in areas such as psychology, physical therapy, or the care and training of the retarded. Of course, day-to-day decisions regarding care--including decisions that must be made without delay--necessarily will be made in many instances by employees without formal training but who are subject to the supervision of qualified persons.[29]

This case should also stimulate training in accepted professional practice and in resolving complaints regarding treatment programs. The first topic requires familiarity with accepted "professional judgment, practice or standards," and the form and manner of documenting that such judgment has been exercised in a particular case. This topic is obviously complex, and the Supreme Court's opinion sheds little light on appropriate practical guides and reference sources. Indeed, Chief Justice Burger casts some doubt on the feasibility of discovering departures from "generally accepted or prevailing professional practices," presumably because of the diversity of such practices. Yet an agency's own internal guidelines, policies, and practices manual, as well as general accreditation and other basic treatment standards, outline certain areas of strong professional consensus. Therefore, both familiarity with and training based upon such texts could assume special importance.

The second issue--training to resolve complaints of safety, restraints or other treatment inadequacy--is also of vital concern to those administering mental retardation facilities. To avoid undue judicial interference and to create an early warning system for rights-related problems, internal grievance procedures should be created or refined. The Third Circuit majority opinion offers a fruitful suggestion: "one effective means of resolving complaints regarding treatment programs would be for an institution to provide an internal grievance mechanism with appropriate procedural safeguards."[30] Achieving this objective clearly requires strengthening the training and rights-related knowledge of human rights officers, human rights committees and independent decision-makers within public and private facilities.

Perhaps the most important--and ironic--lesson of Romeo's case is not to be found in the Supreme Court's opinion. Although those judges assumed that someone with his disability would never be able to leave the institution, Nicholas Romeo today lives in a community living arrangement.

C. Rogers v. Mills and the Right to Refuse Treatment

The seven-year struggle to define the legal rights of Boston State Hospital mental patients to refuse treatment is of national relevance. It will establish a precedent that has potentially broad significance for any treatment facility for persons with mental disabilities. A case of this notoriety can also have a substantial impact on the debate over the limits of client autonomy and the clinical judgment by state professionals that can override autonomy.

1. On Treatment Modalities and Balancing Tests

Few cases at the junction of law and psychiatry have generated as much controversy as Rubie Rogers' effort to refuse "mind-altering" drugs. Dr. Alan Stone, then president of the American Psychiatric Association, described the resulting ruling as the "most impossible, inappropriate, ill-considered judicial decision ever made in the field of mental health law." Advocates for mental patients discount such polemics. In their view, criticism of the cost, delays in treatment, diversion of professionals' time, and regulatory impacts stemming from refusal procedures were exaggerated. They maintained that the mental patient, like any other citizen, need not forfeit autonomy over his or her own body because of that status or the receipt of state care. Professor Alexander D. Brooks, a nationally recognized authority in this field, has taken a similar stance. In a recent study, he concluded that the right to refuse is not only a valid doctrine, but is working--despite the dire predictions--in Massachusetts and elsewhere.[31]

Rather than rehearse this controversy, this discussion outlines the rights and remedies identified at various stages of this litigation. It also stresses the Supreme Court's view of the contrasting protections between federal constitutional law and state law when disputes over treatment modalities hang in the balance. Since all parties acknowledge that the right to refuse treatment is not absolute, the central image in this analysis is that of a balancing scale: the client's interest in autonomy on one side and the state's police power or parens patriae interests on the other.[32] As we will see, the debate rages as to the precise interests involved, the harms and benefits of proffered treatments, the competing conditions which might outweigh the exercise of the right, and tne process and the actors involved in reviewing contested treatment decisions.

2. The Issues at Trial

In a remarkably detailed opinion issued on October 29, 1979, Judge Tauro examined the difficult issues that surround the management of disruptive patients and the legality of medicating or secluding them without their consent. The thirty-eight printed pages of the Federal Supplement given over to Rogers v. Okin canvass the facts, the constitutional basis of the right to refuse, and the remedies available to plaintiffs subject to involuntary or unlawful seclusion or medication.[33] As to the seclusion practices, the court held that the defendants had violated Massachusetts law and Department of Mental Health regulation by impermissibly and

routinely using seclusion as a treatment modality. Thus, seclusion was prohibited except in narrowly defined emergency situations involving committed mental patients. However, the plaintiff's claims for damages were rejected. (Those parts of the court's ruling dealing with seclusion or state tort law were not contested in the litigation heard by the Supreme Court.)

The court held that hospitalized mental patients have constitutional rights, based upon liberty and privacy interests, to decide for themselves whether to accept or decline drug therapy. Because of the finding that civil commitment provides no inference of legal incompetency to make this decision, this judicial ruling applies to both voluntary and involuntary patients. There are two exceptions:

> Medication in an emergency where the failure to use drugs would result in "a substantial likelihood of physical harm to the patient, other patients, or to staff members of the institution."
>
> Medication with the consent of a court-appointed guardian for a patient adjudicated legally incompetent.

3. The Modified Standards on Appeal

The Court of Appeals for the First Circuit modified the legal standards to give treatment staff greater room for discretion. While affirming the constitutional right to refuse treatment as part of the Fourteenth Amendment due process clause and its "penumbral right to privacy, bodily integrity, or personal security," the First Circuit prescribed more flexible conditions and procedures for restricting that right.[34] (This clause secures all persons against any state action which is a deprivation of life, liberty, or property without due process of law). For example, under the state's police power, the court held that a hospital's professional staff may administer involuntary medication on determining that "the need to prevent violence in a particular situation outweighs the possibility of harm to the medicated individual," and that "reasonable alternatives" to the antipsychotic drugs have been ruled out. In terms of the parens patriae justification, the court held that forcible medication is permitted only when necessary to prevent further deterioration in the patient's mental health.

In giving procedural protection to these interests, the court directed the trial judge to develop adequate

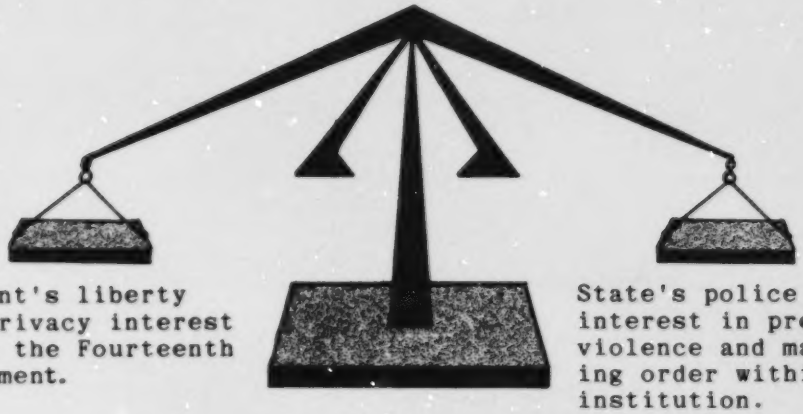
mechanisms. However, it did cut back on the district court's earlier remedies. In essence, the Court of Appeals had adjusted the scale as follows: Mental patient consents to drug therapy or:

a. Staff has substantial discretion in deciding when an impending emergency requires forcible medication. At a minimum, this requires an individualized determination by a qualified physician.

b. If patient is not judicially found incompetent, involuntary medication is permitted only when necessary to prevent further deterioration of his or her mental health.

c. Otherwise, judicial determination of incompetency and medication only if under substituted-judgment test patient would accept such treatment if he or she were to be competent to decide.

d. Some hospital-based determination of the need for forcible medication in a particular instance.



Patient's liberty and privacy interest under the Fourteenth Amendment.

State's police power interest in preventing violence and maintaining order within the institution.

State's parens patriae power to alleviate suffering and provide effective treatment.

4. The Supreme Court Ruling

In keeping with its long-standing policy of avoiding unnecessary constitutional law decisions, the Court vacated the appeals court's judgment and remanded it for a determination of whether Massachusetts law would provide a sufficient legal foundation and remedy. Shortly after the U.S. Supreme Court accepted Mills for review, the highest state court in a separate case, In the Matter of Richard Roe, III,[35] upheld the right of a noninstitutionalized, mentally incompetent person to refuse antipsychotic drugs. The Supreme Court agreed with the counsel for the Rogers patients that Roe might offer an alternative basis for deciding, or at least influencing, the result in Mills v. Rogers.

The Court reasoned that the procedural and substantive liberty interests now guaranteed under Massachusetts law might well exceed the minimum baselines of federal constitutional law. Justice Powell's opinion offered several contrasts between the state laws as interpreted by the Massachusetts Supreme Judicial Court and his own Court's past decisions of constitutional law (see Table 1). For instance, the judicial review and the subjective "substituted judgment" test mandated in Roe appear to be far more stringent tests than the United States Supreme Court would likely interpose between a mentally disabled client and the clinician. If fuller relief for the Rogers plaintiff could be gained under Massachusetts law, a Supreme Court decision of constitutional law might be premature--an advisory opinion prohibited by the Court's own rules of self-restraint and unwanted by the litigants. At the least, the Supreme Court judgment would fall short of the relatively expansive protections for mental patients imposed by the state court.

TABLE 1

Comparison of Legal Protection Between Highest Massachusetts and U.S. Courts

Massachusetts Supreme Judicial Court	United States Supreme Court
Substantive Protections	**Substantive Protections**
Protected liberty interest in refusing unwanted treatment even for persons adjudicated legally incompetent	Compromises between patients' liberty interests and professional capacities to meet more exacting tests of proof required as a "practical consideration"
Under substituted judgment test, incompetent's "values and preferences," "character and circumstances" considered	State interests may be given greater weight or scope
This personal right can be outweighed only by an "overwhelming state interest"	
Procedural Protections	**Procedural Protections**
Judicial determination of substituted judgment before administration of drugs	Judicial fact-finding may not offer the best or more prudent method of decision-making in the mental disability field
Possible emergency exception	
Six relevant, but non-exclusive criteria enumerated in court's guidelines	

5. The Meaning of Mills for Clients' Rights

After the Supreme Court's anticlimactic ruling, it is too early to draw implications for clients' rights or staff training. Clearly, litigation in a wide range of intra-institutional liberty issues may shift from a federal to state-law focus. Indeed, in settling Mills, the federal judges have made a request to the Massachusetts Supreme Judicial Court to answer the potentially decisive state law questions (under a procedure known as "certification"). That court has now held that even a committed mental patient has the right to make treatment decisions unless adjudicated incompetent by a court. Rogers v. Commissioner of the Department of Mental Health 390 Mass. 489 (1983).

Under this decision, objections to psychoactive medication will receive strict scrutiny in the state courts, whether or not an individual is incompetent or is living outside an institution. In principle, the precedent reached in Rogers v. Mills will apply to similar situations affecting the residents of mental retardation institutions. Indeed, some of the named plaintiffs in that case were diagnosed as mentally retarded as well as emotionally distrubed. As various problems and side effects of psychotropic drugs become better and more widely known, demands for stricter legal regulation are likely to follow.[36]

All this has profound implications for both staff training and policy making. Rogers, Roe and the resulting ferment should provoke a thorough review of the checks and balances intended to assure that drugs are used for the residents' benefit and not abused for an institution's convenience. It would be unwise to assume that because residents may not be capable of articulating a clear objection to a drug regiment, an institution has discharged its legal and ethical responsibilities to protect them from excessive drugs. For example, federal cases have already imposed obligations on staff to monitor drugs for serious side effects, including but not limited to tardive dyskinesia.[37] Training in, and adherence to, state laws and regulations are clearly essential first steps. Existing practices and guidelines on this subject should also be reviewed against the standards of federal development disabilities law and relevant court decrees. While damages were denied in the Rogers case, it should be recalled that Judge Tauro's rationales included the policy grounds of the archaic facilities, support staff, and conditions at Boston State Hospital, and the novelty of the legal claim during the period at issue, 1973-1975. As institutional conditions improve and the treatment professions become more aware of

these legal rights, those excusing circumstances may not avail future defendants. Here again, staff should have the training and tools to meet far higher standards of care and habilitation than those necessary to avoid liability for egregious treatment.

D. Rowely v. Hendrick Hudson School District and the Right to Appropriate Education

On June 28, 1982, the Supreme Court, by a six to three vote, decided that the Education for All Handicapped Children Act did not require the best possible education for a deaf child. That result comes as no surprise to those who are familiar with the Act (P.L. 94-142). While the Court only issued a narrow ruling of statutory interpretation, there is a risk that its forty-three page opinion may be misunderstood or distorted by those seeking to cut educational expenditures for the handicapped. This analysis seeks to dispel such misunderstandings.

1. "This Case Is About Amy"

With those opening words, the Court of Appeals emphasized the unique facts underpinning its decision. The case was simply an attempt to aid one eight-year-old girl to obtain a sign language interpreter as part of a "mainstreaming" package of services. The portrait of Amy which emerged from the judicial findings was that of a bright, if not gifted, child who, with her residual hearing, successfully participated in regular elementary education classes.

Described as "remarkably well-adjusted" and socially successful with her peers and teachers, Amy was an excellent lipreader and was academically superior in performance to her nonhandicapped classmates. Perhaps most importantly, she enjoyed the extraordinary support and zealous advocacy of her parents, both deaf, who trained and reinforced her communications skills from birth.

With an I.Q. of 122, "intellectual assertiveness," and an eagerness to learn, Amy made substantial progress and advanced easily from grade to grade. As the only hearing-impaired child in her school, administrators provided her with special services: an FM hearing aid, daily instruction from a tutor for the deaf, and speech therapy. To ensure the success of this mainstreaming, Amy and her parents were shown exceptional professional consideration. School staff attended a course in sign language interpretation, a teletype machine was specially installed for communication with her parents, and teachers used sensitive and accomodating methods

to meet her unique needs. The school balked, however, at one parental request: the services of a sign language interpreter for her academic classes. They did so only after a two-week trial period showed such services unnecessary and of uncertain benefit for Amy. To her parents and to the trial court, the factual issue boiled down to whether such services would lead to greater excellence in her classroom performance.

2. The Lower Court Holdings

The lower courts held that Amy was entitled by law to an interpreter during any academic class. Curiously, however, the trial judge had overlooked the statutory definition of "appropriate education" and instead applied a novel standard. That standard, derived from a Harvard Law Review note, proposed "that each handicapped child be given an opportunity to achieve his full potential commensurate with the opportunity provided to other children." The court further reasoned that this test did not require a school to educate a child to her full potential, but instead required comparative measures of the "shortfall" between Amy's performance and potential and that of her nonhandicapped classmates of "similar intellectual calibre and comparable energy and initiative."

A divided panel of the Court of Appeals for the Second Circuit upheld this equal educational opportunity standard. The majority stressed the unique and sympathetic facts of Amy's plight. They even took the unusual step of denying any precedential effect to their decision in any other case. Nonetheless, the dissenting judge feared a flood of litigation and criticized the speculative and difficult educational comparisons envisioned by the trial judge.

3. The Supreme Court Ruling

Rowley represented two "firsts" in the Supreme Court's history. As an example of the Court's own accommodations to handicapped persons, it authorized special electronic equipment in the courtroom so that a deaf attorney could argue Amy's case. More significantly, it marked the Court's first interpretation of P.L. 94-142 and hence its first foray into the realm of special education.

In rejecting the lower court's "full potential" standard, the Court held that the school authorities were not obligated to provide Amy with an interpreter. The majority ruled that the statutory guarantee of a "free appropriate public education" required states to provide "personalized instruction with sufficient support services to permit the child to benefit educationally from that instruction." They

viewed P.L. 94-142 as mandating "a basic floor of opportunity," variously described as "meaningful" access to public education and as "specialized instruction and related services" designed to meet the unique needs of each handicapped child. In explicitly recognizing that the Act covers a range of children from those labeled profoundly retarded to those with mild handicaps, the Court declined to adopt any global test for "determining the adequacy of educational benefits" conferred upon handicapped children. With great care, Justice Rehnquist confined his analysis to the situation of a mildly handicapped child integrated in a regular school setting.

Where does this leave the educator of mentally retarded children? The Court noted that Congress intended that services for handicapped children, regardless of the nature or severity of their disability, be educationally beneficial. Thus for some mentally retarded children, attaining personal independence or even basic self-help skills would constitute sufficient benefit, whereas others could aim for goals well beyond mere self-sufficiency. Given this wide spectrum of abilities and disabilities, the Court construed the Act as offering a definitional checklist rather than a single, clear prescription of what constitutes an appropriate education.

As the Court's opinion states, the elements on that list include:

- Personalized instruction and support services of benefit to the handicapped child
- Public education provided free of charge
- Instruction and services meeting the state's educational standards
- Education complying with the child's individualized educational plan (IEP)
- The active involvement of the child's parents or guardian in the IEP process
- The opportunity to pursue due process hearings and judicial reviews when parents are dissatisfied in order to ensure that both procedural compliance and substantive requirements under the Act are satisfied

- For the handicapped child placed in a regular educational setting, educational progress as measured by examinations, grading, and advancement to higher grades

- For handicapped children generally, preference for mainstreaming (i.e., the least restrictive educational environment suited to the child's individual needs)

This is a formidable checklist. Furthermore, state and federal courts still retain substantial powers of review in matters of what constitutes a "free appropriate public education." Courts are not limited to ensuring compliance with the Act's procedural requirements. That is only the first step in the inquiry into whether the individualized educational program developed under the IEP process is "reasonably calculated to enable the child to receive educational benefits."

Although the courts are admonished not to substitute their own notions of sound educational policy or preferable educational methods for those of the states, courts can still disagree with the substance of a state's proposed plan or order additional relief. As in Romeo, there is again a call for due deference to the judgments of state professionals. But unlike that decision, the courts, without entering the thickets of educational theories, will have a freer hand in overturning deficient IEPs than in awarding damages for deficient habilitations efforts.

4. Implications for Communitization and Clients' Rights

Read properly, Rowley reaffirms the basic thrust of P.L. 94-142: the educability of all handicapped children and a preference for mainstreaming whenever that is consistent with a child's individualized needs. Indeed, the Justices rely heavily on the landmark "right to education" cases of Mills v. Board of Education and P.A.R.C. v. Pennsylvania, which firmly established both those propositions and the constitutional groundings for the statutory mandate which followed.[38]

The dissent, however, is also correct in noting the majority opinion's mischaracterization of those cases. Mills and P.A.R.C. required more than just opening the schoolhouse door to the excluded or some token education for the handicapped child. They required substantial equality of educational opportunity with nonhandicapped children, and as in

Mills, an explicit standard of educational quality; i.e., for every child with a mental or physical handicap, "a free and suitable publicly-supported education" as measured against and suited to each child's needs. Those principles remain the true foundations of P.L. 94-142.

Advocates may nonetheless take heart at the Supreme Court's reaffirmation of mainstreaming, the basic benefits under the Act, and the central role for involved parents and guardians in ensuring that handicapped children receive all those benefits to which they are entitled.

But what of children, who through the death, distance or disinterest of parents, lack this familial protection or the "ardor" of a substitute representative? While P.L. 94-142 requires "surrogate representatives" for such children, cases like that of Phillip Becker are well-publicized reminders that some mentally retarded children have been denied, or had postponed, assistance of that type. Not every child is as privileged as Amy Rowley in having two parents so dedicated to her well-being and the maximization of her human potential. Every handicapped child deserves, at the least, a spokesperson trained to recognize and defend his or her rights. The same is true for incapacitated mentally retarded adults in out-of-home placements.

Beyond its impetus to rethink advocacy provisions, Rowley is a symbol that communitization works. Not too long ago, a child with Amy's disabilities might have been shunted to an isolated residential state school for the deaf rather than being welcomed into her neighborhood school. This example and the precedent in Rowley can also be turned to the advantage of children with mental retardation.

Lower courts can continue to review the merits of a school district's placement plans. They can even order residential educational services for severely retarded children who cannot derive educational benefit without the continuity and consistency of approach available in a round-the-clock educational program. In the federal Massachusetts case of Abrahamson v. Hershman, the First Circuit upheld that result.[39] For Daniel Abrahamson, whose remarkably profound disabilities and risks of regression place him worlds apart from Amy Rowley, the court ordered either a residential school or a day program and a group home "providing a structured environment" giving "consistent instruction" and "continual reinforcement" of the skills taught in school. For, as the Supreme Court noted in Rowley, the Act provides for the education of "some handicapped children" in separate classes or residential settings in order to provide them

opportunity for some educational progress. Moreover, "it would do little good for Congress to spend millions of dollars in providing access to a public education only to have the handicapped child receive no benefit from that education." With appropriately trained staff and teachers with access to both suitable methodologies and the advice of experts in the field of special education, no child need suffer that fate.

5. Postscript on Amy Rowley

As the 1983-1984 school year began, the Rowley's quest for a sign-language interpreter for Amy continued. The school district insisted that Amy is making progress without one, her parents disputed the appropriateness of her education, and further administrative hearings were expected. Although the Rowleys have offered to pay the expense of a classroom-based interpreter, the school district has refused on grounds that its educational philosophy is better for Amy. Meanwhile, the costs of litigation far outstrip the annual costs of such an interpreter. The Rowley's pro bono counsel submitted a motion for $400,000 in attorneys fees (denied by the court), and the school district's legal fees exceed $100,000. Despite these burdens, no compromise settlement is now anticipated and the dispute goes on.

IV. Exercising Rights

Turning declarations of rights into actions that improve the day-to-day lives of persons with disabilities is a critical responsibility. It is a responsibility shared by legislators, administrators, judges, professionals, disabled persons, families, and the general public alike. Diffuse responsibilities can, however, become forgotten responsibilities. The following pages survey a few of the methods that can upgrade the quality of care, safeguard individual rights, and help consumers to identify and exercise their rights.

A. Professional Responsibility

The ethical responsibilities of professionals should be the first line of defense for the rights of clients. According to the American Association on Mental Deficiency (AAMD), "professionals in the field, individually and in concert, should assert leadership in the protection of these rights, in assuring their exercise and enjoyment by retarded citizens, and in the implementation of these rights to provide more satisfying circumstances of life for retarded persons."[40] To this end, the AAMD, acting as amicus curiae in the Phillip Becker case, supported his rights and the rights of other mentally retarded children to medical care, habilitation, and emotional support.[41] Similarly, on May 29, 1983, the AAMD Council authorized appropriate actions in legislative, executive, and judicial forums to vindicate its long-established position that the existence of mental retardation is no justification for terminating the life of any human being. In a recent comment on the Department's proposed regulations, the Association has urged that nondiscriminatory medical treatment of disabled infants is required on equal protection grounds, as well as justified by state-of-the-art advances in habilitating persons with severe to profound disabilities.[42]

Beyond such causes celebres as Doe and Becker, professionals have a clear ethical obligation to consider the rights of mentally retarded persons in all aspects of their work. Professionalism also entails a duty to speak out when those rights are contravened. Conscientious professionals have therefore taken steps to realize their clients' legal and human rights through such activities as:

- training clients to exercise their rights
- training others as to clients' rights
- designing services and facilities

- preparing IHP's and IEP's which respect client choices and normalization goals
- testifying before legislative and judicial bodies
- direct work with clients
- administrative and regulatory action
- advising self-advocacy groups
- community education
- teaching
- publishing
- whistleblowing
- counseling co-workers

B. Self-Advocacy

Advocacy by persons with disabilities for their own individual and collective ends is an important tool for independence and growth. Self-advocacy can be defined as persons asserting their own rights, expressing their needs and concerns, and assuming the duties of citizenship to the extent of their capabilities. In Minnesota, for example, Advocating Change Together, Inc. (ACT) is run by people who are mentally retarded. ACT has won legislation to protect consumers from inappropriate aversive and deprivational therapy; supported consumers as they stand up for their own rights in their places of employment and residence; and helped increase public awareness that their members are capable of thinking, speaking and acting for themselves.[43] Even in institutions, such as the Belchertown and Syracuse centers, self-advocacy groups are at work to change the participants' attitudes and the (sometimes demeaning) practices of others. As Gunnar Dybwad and this author conclude, self-advocacy is a "new force in the human services field that will not fade away but will increasingly improve the community's perception of persons with mental retardation in terms of their capabilities and potential."[44]

C. Family and Lay Advocacy

At various stages in our lives, we will all need the support and zealous aid of family members and friends in a

world that can be harsh and bewildering. Persons who are mentally retarded are no different. Some adults may need support and aid on a more continuous basis. Others will get by with substantial independence and call upon others to help in a crisis or a new situation. Yet some advocacy tasks are universal. As the discussion of the Rowley case should have made clear, parents or surrogate parents play a decisive role in the educational planning that must equip a handicapped child for a life of growing independence as well as interdependence on others. Whether it is shaping a child's individualized educational plan or asserting an adult's right to privacy and personal expression, the persuasive and supportive activities of family members or lay advocates can make a large human difference. Together with self-advocates, legal allies and conscientious professionals, these highly motivated advocates can constitute a formidable political force.

D. Legal Advocacy

In this monograph and elsewhere, I have described examples and rationales for the assertion of legal rights.[45] Further elaboration is not required here. Two points, however, deserve specific mention. Recent cutbacks in the Legal Services Corporation have reduced the ability of disabled people to protect their basic survival entitlements and liberties. This represents a callous political act which must be reversed. When a disabled person's SSI benefits are terminated, access to a legal services attorney can be the decisive factor to their restoration.

The second point concerns reform litigation. For over a decade, class action suits against dehumanizing care have given visibility to the legal rights and human needs of vulnerable people. What happens if federal judges tire of this Sisyphean struggle to erect and maintain decent standards of care in public facilities for the mentally disabled? Events unfolding in Massachusetts may give us a clue as to whether we can institutionalize remedies without institutionalizing masses of people.

In a report to U.S. District Court Judges Tauro and Freedman, I investigated and determined the need for trained, independent advocates to protect the rights of mentally retarded and mentally ill clients in six major cases. As a court-appointed expert, one of my central conclusions was that "the existence of a functioning, ongoing advocacy system should be viewed as an important criteria in the decision to relinquish retention of jurisdiction in the six class action lawsuits.[46] Various sections of that report detailed the

rights at stake for mentally retarded citizens, unmet priority advocacy needs, and the structural and manpower requirements for conducting advocacy functions in this specialized setting.

On the mental health side, this report led to recommendations by the court monitor and, ultimately, to an order by the trial judge to implement the proposed advocacy system. Based on these reports and oral evidence, Judge Freedman issued factual findings on the absolute necessity of advocacy services to achieve the purposes of the Brewster v. Dukakis decree. On appeal, the defendants conceded that "an independent legal advocacy program is highly desirable," but disputed the district court's legal power to compel the Commonwealth to fund the proposed program. The U.S. Court of Appeals for the First Circuit agreed with this argument and held that a general legal services program for the mentally ill was not closely enough related to the Brewster consent decree's basic deinstitutionalization goal. However, this decision does not foreclose the possibilities of a more narrowly focused advocacy plan or the implementation of the original plan through other financial sources.

On the mental retardation side, no definitive action has been taken. After a period of consultation, further fact-finding and the appointment of the court monitor as a special hearing master, the parties suspended negotiations or efforts to secure formal action by the monitor's office. The issue still remains in limbo, despite the evidence that an advocacy system accessible to vulnerable Department of Mental Health (DMH) clients can constitute an early-warning system, alert staff and outsiders to dangerous flash points, provide a needed presence, and articulate the concerns and rights of silent or unassertive clients.

In contrast, the parties in Pennhurst and Willowbrook have established a requirement for advocacy services for clients who might otherwise be individually unrepresented. This concept is a compelling one. In a final settlement of an institutional reform or deinstitutionalization case, the existence of advocacy and monitoring mechanism can avoid a slide into the chaos and arbitrariness of the past. Since generic advocacy services are shrinking, specialist advocacy services must be available in their stead.

E. Human Rights Committees

The rapid growth of human rights committees is an illustration of the room for citizen initiative in this field. Because of their relative novelty but wide accep-

tance, I will describe in some detail these committees' goals, auspices, functions, problems, and potentials. Under Medicaid regulations for Intermediate Care Facilities for the Mentally Retarded, ICF/MRs must have standing committees on human rights and must encourage each resident to exercise his or her rights as a resident and as a citizen.[47] Requirements for human rights committees (HRCs) also stem from accreditation standards, AAMD positions papers, judicial orders, state laws and regulations, and administrative policies.[48] These mandates reflect assumptions that (1) preventive measures can avoid violations of rights, (2) retarded persons are especially vulnerable to violations and abuses since they often lack the means of effective complaint, (3) such committees can improve the policies, reality, and spirit of safeguarding individual rights. In theory, HRCs as part of an efficient grievance mechanism can also offer a potential alternative to settling some disputes in court.

Landmark judicial decisions set in motion human rights committees and similar oversight agents. In 1972, through a pioneering "right-to-treatment" decree, Judge Frank Johnson created seven-member human rights committees at Alabama's Bryce, Searcy, and Partlow institutions. Under the Wyatt standards, these HRCs were to be the "eyes and ears" of the court and were to review all habilitation or rehabilitation programs to "ensure that the dignity and human rights" of the residents were preserved. Specifically, these duties included:

- Reviewing and approving behavior modification programs involving noxious or aversive stimuli,
- reviewing and approving any unusual or hazardous treatment procedures,
- reviewing and approving any experimental research on residents,
- reviewing and approving any proposals for organ transplantation or any other surgical procedure undertaken for reasons other than therapeutic benefit to the resident,
- receiving investigative reports on incidents of alleged mistreatment, neglect or abuse in any form,

- advising and assisting residents who complained of infringements of their legal rights or the defendants' failure to comply with the Wyatt standards.

The lack of professional staff to assist these citizen committees seriously limited their effectiveness. Learning from this experience, litigators in later cases designed more powerful monitoring and enforcement arrangements, such as the Willowbrook Review Panel, the court-appointed monitors in Massachusetts, or the special masters and their staff in Pennhurst, Plymouth, and elsewhere. Indeed, consent decrees were sometimes modified to take such needs into account. Thus, appellate rulings in the Willowbrook case upheld the appointment of a special master and the staffing of the Citizens Advisory Board so that it might fulfill its in loco parentis functions.[49]

State laws have also expanded the authority and functions of human rights committees and other watchdog commissions. The Florida Human Rights Advocacy Committees are a notable example. The idea was sparked by Leo Plotkin, a parent and a local businessman, who started a committee at a scandal-plagued Miami institution. From this beginning in 1972, Plotkin and the Association for Retarded Citizens negotiated an agreement for HRCs in all public retardation institutions. By 1975, Florida adopted a law giving human rights advocacy committees the power to discover, receive, and investigate complaints of abuse or deprivation of the constitutional and legal rights of any client of the State Department of Health and Rehabilitation Services. Organized in 24 district committees, some 230 volunteers (including consumers, lawyers, physicians, and other professionals) review the wide-ranging problems and complaints of developmentally disabled persons, welfare recipients, mental patients, juveniles, and nursing home residents. A Statewide Human Rights Advocacy Committee, appointed by the Governor, has supervisory training and "appellate" responsibilities for making this structure work. Over the years, these committee have acquired additional statutory duties such as:

- reviewing departmental programs or services and making recommendations as to their effect on the rights of clients,
- reviewing research projects involving human subjects,
- receiving notices of alleged incidents of abuse and "Unusual Incident Reports" involving disabled clients,

- accepting appointments as "representatives" (defined as patient's advocates or friends) for persons civilly committed to mental hospitals,

- assisting retarded persons in the formation of "resident self-government councils" in state facilities.

State regulations have also mandated human rights committees for community and institutional programs. In Massachusetts, these committees are empowered to monitor the implementation of clients' human and civil rights in state schools, mental hospitals, and licensed community programs. While some HRCs in institutions have been in existence since 1971, committees in community-based services have only recently been organized or are in process of being organized.

According to Department of Mental Health regulations, such human rights committees are supposed to "review, monitor, and investigate the activities of the program with regard to the human and civil rights of the persons served by the program."[50] Specifically, they are authorized to investigate alleged client mistreatment; monitor aversive and deprivation techniques of behavior modification; review and monitor the use of chemical, physical, and mechanical restraints; monitor the means to inform and train clients on their rights; and take affirmative action to strengthen opportunities for clients to exercise their rights.

Regulations on investigations, effective in 1983, further define and strengthen the role of human rights committees as protectors of client interests. HRCs now have legal standing to file complaints for clients or to take other steps to safeguard a functionally incompetent client in an investigation.

The composition of these HRCs must include consumers, parents, and/or advocates of consumers; a physician, allied health professional, or psychologist; and an attorney, paralegal, or law student. At a minimum, they must have five members, but additional members can be appointed by the program's executive.

Although their origins may differ, human rights committees share many common pitfalls and problems. Their powers are limited and their roles are often ambiguous. When recommendations are ignored, their advisory, fact-finding, educative, and advocacy roles are undermined. Lack of expertise and lack of independent sources of information can

also prove frustrating. Committees appointed by superintendents or primarily composed of facility staff may lack independence. Without adequate support staff, a clear agenda, and a sense of direction, the limited time of committee members can be squandered on repetitive, inconsequential, or ill-suited tasks. All too often, committees that meet only monthly or less frequently are overloaded with responsibilities.

Yet this model of citizen review has many commendable features and should be strengthened. Some of the answers to its present limitations involve policy reforms, increased recognition, staffing, training, and links to independent advocates. Effective committees must have professional staff (in some places designated as human rights officers) who can do the investigatory "legwork," gather information, and follow through on HRC recommendations and projects. Training in the substance of clients' rights, the techniques of program reviews, and the processes of negotiation and monitoring is also essential. Perhaps the most critical step toward increasing the capacities of HRCs is to bring them into closer working relationships with the external advocates and coalitions committed to change and to clients' rights. Policy changes could add to the power base of the HRCs and improve their ability to serve as investigatory backstops, forums for informal dispute resolutions, and sources of informed recommendations. For performing a selfless, taxing, and often disturbing task, persistent HRC members deserve recognition.

Human rights committees have a legitimate function as the creative gadflies of a human services program. One of their principle missions is to "spot the issues" of possible noncompliance with human and civil rights norms and to bring those issues to the attention of the administration for further investigation and remedial action. In this way, committee members can conserve their time and energies and place managerial accountability where it properly belongs--on management.

A few illustrations will suffice. In Maryland, a human rights committee became concerned about the lack of opportunities for competent clients to vote in general elections. Their recommendations not only led to a voter registration campaign in a state institution, but also prompted a statewide review of policies to encourage eligible clients to exercise the franchise.

The federal Education for All Handicapped Children Act (P.L. 94-142) requires each state to establish a program of

"surrogate parents" for children who are wards of the state or who lack familial support.[51] Yet in many states, this valuable and essential means of safeguarding a vulnerable child's educational rights is not being provided, and the lack of such appointments or the planning to do so goes largely unnoticed. Human rights committees and other concerned citizens can speak out.

Another example centers on the free exercise of religion. Most states expressly guarantee religious freedom to clients in public or licensed care facilities. But when services are held in buildings inaccessible to residents with physical handicaps, or when transportation is unavailable to permit residents to attend services in the community, this freedom is inhibited.

A final example involves the right to least restrictive alternatives even within institutions. When residents are confined to locked wards or cottages for reasons unrelated to their safety or clinical needs, a substantial legal and human rights issue is raised. Moreover, if the rationale for this undue restriction is the needs of <u>other</u> more severely retarded or disturbed residents, issues of associational freedoms and protection from harm may be involved. Human rights committees may not always have the information or the expertise to answer these questions, but they certainly have the right to ask these questions.

As previously emphasized, the committee also has an important oversight role in the areas of rights training and clients' exercise of rights. It can only discharge that function properly if its own members receive some training in these areas and have the opportunity to review those materials or general plans by which a facility intends to raise consciousness or knowledge of client rights.

Ideally, members appointed to human rights committees would have some prior background or professional familiarity with this subject matter. However, this will not always be the case. In any event, a well-developed human rights program should provide a central or regional resource center containing up-to-date materials, a manual for committee members and staff officers, and a collection of case studies on effective interventions by committees of this type.

In closing, two further points should be stressed. Under various conditions, human rights committees can shift between various roles and stances: advisor, investigator, monitor, advocate, and agent for change. However, unless a committee sets some priorities and goals for itself, its

agenda can easily be monopolized by the demands of institutional maintenance: paper reviews, distracting side issues, the burden of seeing every abuse complaint and every order for restraint. Unless such devices as subcommittees, spot checks, delegation to staff and other advocates are put into play, committees will have great difficulties in priority setting and outreach efforts.

To be effective, human rights committees and their staff officers cannot operate in a vacuum. They need to be in close and regular communication with administrators, legal counsel, independent advocates, clients, and others involved in related human rights tasks. That is a considerable challenge, but it offers considerable dividends and satisfactions for the creative people who are attracted to the human rights mission.

Conscientious committees do succeed in ventilating important human rights concerns. They can be a vital part of the transmission belt that links the pronouncements of supreme courts or state legislatures to the changes that must take place at the grassroots level. By enlisting alert and talented citizens with an independent outlook, they can offer human services programs a fresh perspective on how better to safeguard clients' rights and improve the quality of their lives. In short, they represent a citizen's voice amid the professional chorus.

There is also a larger purpose behind this. Historically, American political processes have not deserved great trust when the rights of people with mental disabilities are at stake. They compose one of our hidden minorities. Because the rest of us have insisted on seeing such minorities as "different," as Harvard Law Professor John Ely explained, they have been rendered "unable to participate effectively in the usual pluralistic give and take."[52] At its core, the human rights movement aims to make them seen. And in time, client participation and self-assertion will follow. Then political trust can be fully restored.

V. Themes and Topics for Further Study

One hundred and thirty years ago, Charles Dickens satirically described the lawyers' realm as a "perplexed and troublous vailey of the shadow of the law, where suitors generally find but little day."[53] On the contemporary legal landscape, persons with disabilities are trying to reverse that image--to use our justice system to escape the shadow of impoverished existence. But as I have tried to suggest, their movement for human rights and personal dignity far transcends an appeal to the courts or to adversarial processes.

That movement requires the collaboration of many allies. Those who plan and provide habilitation services have especially vital roles. What follows is an attempt to summarize the themes of this monograph and to point out some of the unsettled issues in human rights deserving of further reflection and activism.

Pervasiveness

The field of developmental disabilities is infused by human rights and civil rights concerns. This influence is not only pervasive, but likely to be permanent. Are professionals, paraprofessionals, and consumers adequately trained to understand the benefits and risks of this human rights revolution?

Intensification

The genie is now out of the bottle. As a mood of consumer assertiveness spreads and faith in old sources of paternalistic authority ebbs, categorical restrictions and obsolescent care patterns will be increasingly challenged. For example, does being labeled mentally retarded disqualify a job-seeker from a governmental security clearance? Or life in a family-sized home? Or sexual expression?

Equality

The civil-rights movement for disabled persons is pressing for equal treatment for persons who may have unequal natural capacities or aptitudes. How far and at what expense must the general society offer accomodations that will permit persons with disabilities to enjoy opportunities for which they are qualified?

Caution Signals

The U.S. Supreme Court has issued a number of recent opinions that seem designed to brake expansive interpretations of the rights of disabled persons. For example, their decisions give increasing weight to the cost factors in implementing those rights, the deference due to state professionals, and the supposed limited expertise of courts to adjudicate matters of educational, habilitational, or psychiatric dispute. Do these decisions represent a temporary swing on the pendulum, or a durable check on the discretion of lower court judges?

Undue Deference

It is one thing to leave qualified professionals sufficient latitude to make day-to-day habilitation decisions without the threat of damages for simple mistakes or differences in treatment philosophies. It is quite a different matter to insulate state bureaucrats from injunctive or declaratory review of their policy decisions or their overall placement plans because this, too, deals with "habilitation." Will courts avoid this hazardous misreading of Romeo and be free to test disputed expert testimony by their customary methods?

Legitimacy

Persons with mental and/or physical handicaps do have enforceable legal rights and courts have a legitimate and viable role in securing them. Although the debate on the proper scope of judicial review boils on, the highest U.S. lawmakers have resolved that these rights are real and susceptible to judicially manageable relief. Will this affirmation of legal rights also speed changes in public attitudes and actions?

Diversity

Federal courts are not the sole guardians of civil rights. In many places, state courts by interpreting their own state constitutions and laws may yield results favorable to litigants with disabilities. But will such litigants find the advocates and supportive friends and relatives to help them bring their claims? Can we find and apply alternative ways to prevent or settle human rights disputes without going to court?

Universality

The human rights proclaimed for disabled persons, whether by the U.N., other international agencies, or state and federal governments, pose complex ethical, legal, and socio-economic problems. But at their core they are questions of the spirit: of acceptance, sharing, solidarity, and enlightened self-interest. If this is so, law is not the only engine that drives this human rights movement. It must be powered by a sense of community and compassion. If we wait for courts and legislators to give us "mandates" to do what is right, will our brothers and sisters with disabilities receive what they deserve?

Professionalism

The difference between a business and a profession is the degree to which it defends its clients. At many points, this monograph has described forms of responsible professionalism to promote the legal and human rights of clients with disabilities. Will such professionalism be practiced, recognized, and even rewarded?

Self-determination

Self-advocacy groups and efforts are emerging in the United States and abroad. This is a positive force not only for the realization of human rights, but also for the individual's growth and self-esteem. Yet as one careworker commented, "we all had to get used to the idea of resident empowerment and learn not to fear it." Will we go further and let people speak for themselves?

NOTES

[1]Barr, "Moral Paranoia," Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons 522, 531 (1895).

[2]Mental Health Association of Minnesota v. Schweiker, 554 F. Supp. 157 (D. Minn., 1983)

[3]See City of New York v. Secretary of Health and Human Services, 7 MDLR 88 (E.D.N.Y., filed February 8, 1983).

[4]W. Gellhorn, When Americans Complain: Governmental Grievance Procedures (Harvard University Press, 1966).

[5]Id. at 141. In response, legislatures have created special advocacy services to safeguard the legal and human rights of persons institutionalized as mentally disabled.

[6]Pennhurst State School and Hospital v. Halderman, 451 U.S. 1 (1981).

[7]On the troubled history of compelling state officials to organize and fund certified lay advocates, see Halderman v. Pennhurst State School and Hospital, 555 F. Supp. 1142 (E.D. Pa. 1982); 555 F. Supp. 835 (E.D. Pa. 1983).

[8]See, e.g., 555 F. Supp. 1138 (.E.D. Pa. 1982).

[9]555 F. Supp. 1144, 1160 (E.D. Pa. 1983).

[10]On the legal bases and implementation records of Willowbrook-type cases, see S. Herr, Rights and Advocacy for Retarded People 72-78, 123-135, 171-189 (1983).

[11]393 F. Supp. 715 (E.D.N.Y. 1975) (consent decree approved); 551 F. Supp. 1165 (E.D.N.Y. 1982) (findings of noncompliance; special master appointed).

[12]New York State Ass'n for Retarded Children, Inc. v. Carey, 706 F.2d 956 (2d Cir. 1983).

[13]"Psychologist accuses society of genocide of weak, helpless," Toronto Star, August 1981; Memo letter from Wolf Wolfensberger to Stanley Herr, Aug. 4, 1983.

[14]Smith, "Down's syndrome, amniocentesis, and abortion: Prevention or elimination," 19 Mental Retardation 8, 10-11 (February 1981).

[15]561 F. Supp. 395, 399-400 (D.D.C. 1983).

[16]Id. at 402-403.

[17]Annas, "Disconnecting the Baby Doe Hotline," 13 The Hastings Center Report 14, 16 (June 1983).

[18]E.g., "Model Statue to Establish the Right of Developmentally Disabled Infants to Receive Emergency Medical Care and Treatment," in Disabled Persons and the Law: State Legislative Issues 88-98 (B. Sales, D. Powell, R. Van Duizend & Associates, 1982); California Senate Bill No. 1137 (as amended May 5, 1983).

[19]Reporters' Transcript 1788, Guardianship of Becker, 188 Cal. Rptr. 781 (App. 1983).

[20]In re Phillip B., 92 Cal. App. 3d 796, 803 (1979), cert. denied sub nom. Bothman v. Becker, 445 U.S. 949 (1980).

[21]Youngberg v. Romeo, 102 S.Ct. 2452, 2463 (1982).

[22]104 Code of Massachusetts Regulations, 20.14(2)(c) 1-4 (1980).

[23]See Kremens v. Bartley, 431 U.S. 119 (1977); Secretary of Public Welfare v. Institutionalized Juveniles, 442 U.S. 640 (1979); Rennie v. Klein, 653 F.2d. 836 (3d Cir. 1980).

[24]O'Connor v. Donaldson, 422 U.S. 563 (right to liberty for a state mental hospital patient).

[25]102 S. Ct. at 2462.

[26]Id. at 2460 n.25. A justiciable question is one which may be properly decided by a court.

[27]Id. at 2461.

[28]Id. at 2462.

[29]Id. at 2462 n.30.

[30]644 F.2d 147, 169 n.58 (3d Cir. 1980).

[31]See Brooks, "The Constitutional Right to Refuse Antipsychotic Medication" 8 Bulletin of the American Academy of Psychiatry and Law 179 (1980).

[32]Parens patriae is derived from the medieval concept of the King as father of his people. The concept in the United States is used as a justification for the state's protective powers over certain persons under a legal disability.

[33]478 F. Supp. 1342 (D. Mass. 1979).

[34]Rogers v. Okin, 634 F.2d 650, (1st Cir. 1980), vacated and remanded sub nom. Mills v. Rogers, 102 S. Ct. 2442 (1982).

[35]421 N.E.2d 40 (1981).

[36]See Plotkin and Gill, "Invisible Manacles: Drugging Mentally Retarded People," 31 Stanford Law Review 637 (1979); Clites v. Iowa, 322 N.W.2d 917 (Iowa App. 1982) ($760,000.00 damages awarded for negligent administration of tranquilizing drugs resulting in tardive dyskinesia).

[37]Wyatt v. Stickney, 344 F. Supp. 387, 402 (M.D. Ala. 9172); Wuori v. Zitnay, No. 75-80-SD (D. Me., July 14, 1978) (consent decree, standard 0.5).

[38]348 F. Supp. 866 (D.D.C. 1972); 334 F. Supp. 1257 (E.D. Pa. 1971). These were the first two federal cases to mandate suitable education for retarded and other handicapped children.

[39]Abrahamson v. Hershman, 701 F.2d 223 (1st Cir. 1983).

[40]Position Papers of the American Association on Mental Deficiency at 1 (approved by the AAMD Council 1973-1975).

[41]Guardianship of Phillip Becker, 188 Cal. Rptr. 781 (App. 1983), "Brief of Amici Curiae the Association of Retarded Citizens of the United States; American Association on Mental Deficiency; Association for Retarded Citizens--California; Protection and Advocacy, Incorporated for the State of California (Aug. 19, 1982).

[42]Letter from the American Association on Mental Deficiency to the Director of the Office of Civil Rights, Department of Health and Human Services (August 30, 1983) (commenting on proposed rule, "Nondiscrimination on the Basis of Handicaps Relating to Health Care for Handicapped Infants").

[43]See J. Mohr, Whatever You Decide: A Workbook for Teaching People Who Are Mentally Retarded How to Make Choices and Assert Themselves (ACT, 1983).

[44]G. Dybwad, "Foreword at x, S. Herr, Rights and Advocacy for Retarded People (1983). See id. at 214, 229.

[45]Id. at 211-251; S. Herr, Advocates for People with Mental Disabilities: Report to the United States District Court Monitors on Advocacy Needs and Models for Massachusetts Class Clients (Sept. 1980, 272 pages with reference and appendices.)

[46]S. Herr, Advocates for People with Mental Disabilities at 147.

[47]42 C.F.R. Section 442.404(d)(1): 442.413(a) (1982).

[48]E.g., Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, Standards for Services for Developmentally Disabled Individuals 62 (1980); American Association on Mental Deficiency, supra note 40, "Human Rights Review and Protection Boards," "Use of Physical, Psychological and Psychopharmacological Procedures to Affect Behaviors of Mentally Retarded Persons," 24-26, 33-38.

[49]N.Y. State Association for Retarded Children v. Carey, 596 F.2d 27 (2nd Cir. 1979); 706 F.2d 956 (2nd Cir. 1983).

[50]104 Code of Massachusetts Resolution 20.14(1)(b) (1980).

[51]20 U.S.C. Section 1415(b)(12)(B) (1978).

[52]Ely, "On discovering fundamental values," 92 Harvard Law Review 1, 7 (1978).

[53]C. Dickens, 2 Bleak House 1 (1884; 1st ed. 1853).

ABOUT THE AUTHOR

STANLEY S. HERR is a visiting associate professor at the University of Maryland School of Law. A graduate of Yale College and the Yale Law School, he also holds a doctorate in law from Oxford University. Since 1970, he has been involved in the field of law and mental disability as a public interest lawyer, researcher, clinical teacher, lecturer, and consultant. Dr. Herr was a Rockefeller Foundation Fellow at the Columbia University Center for the Study of Human Rights, a Kennedy Fellow at Balliol College, and a Legal Services Fellow at Harvard Law School. He has also served in various positions in the American Association on Mental Deficiency, the International League of Societies for Persons with Mental Handicap, and the National Legal Aid and Defender Association. Dr. Herr is the author of Rights and Advocacy for Retarded People (Lexington Books, 1983), and a coauthor of Legal Rights and Mental Health Care (Lexington Books, 1983).

Rights and Advocacy for Retarded People

Stanley S. Herr
University of Maryland

Foreword by Gunnar Dybwad

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ABOUT THE YOUNG ADULT INSTITUTE

BY JOEL M. LEVY
Executive Director

Caring For Mentally Retarded Disabled People For Over A

AN OVERVIEW

The Young Adult Institute is a not-for-profit, nonsectarian organization providing a full range of counseling, training, treatment, and residential programs to mentally retarded and developmentally disabled persons in more than 30 programs in the Greater New York area. We serve over 1,000 individuals each day.

For the past 27 years YAI has dedicated itself to providing quality programs and services to mentally retarded and developmentally disabled children, adolescents and adults; to relieving the burden of and bringing peace of mind into the lives of families of mentally retarded or developmentally disabled people; and to advocating for the full human and civil rights of the people for whom we care, and for those still awaiting service.

As pioneers in the promotion, development and implementation of community-based residential and clinical programs, we have assisted and witnessed countless mentally disabled individuals progress from dependency and isolation to a more productive, self-sufficient and integrated role in society.

All YAI programs are based on the principle that mentally retarded and developmentally disabled people are entitled to the opportunity to achieve their fullest potential, and that they are capable of participating in making decisions and choices.

Essentially, the Young Adult Institute exists to make a positive difference in the lives of mentally retarded and other developmentally disabled persons. Our work is based on the belief that developmentally disabled persons have potential for growth and development at any age and at all levels of functioning. The level of independence each can attain depends in large measure on the quality of care received, the sensitivity and understanding with which it is administered, and the extent to which it is related to the need. In all our programs and services, we never lose sight of the individual.

The Young Adult Institute has experienced much growth and development in its young history. Statistics alone do not tell the full story, but they provide an impressive record. In 1970, we were serving 150 clients. In 1984 we served over 1,000 clients and their family members. The core of our program a decade ago was a 17 hour-a-week course provided by our adjustment center in Manhattan. Today we provide services 24 hours-a-day, seven days a week, throughout New York City and Westchester County. In 1984, the Young

nd Developmentally
Quarter Of A Century

YAI means caring for each other

Adult Institute and Workshop will provide over one quarter million client visits which include both residential and rehabilitative services. Our agency now provides a full continuum of services to individuals in all functioning levels through a carefully structured matrix of programs.

THE DAY TREATMENT PROGRAMS

YAI offers a carefully structured curriculum for clients with profound, severe and moderate retardation. The program includes activities of daily living, prevocational training and adjustment to the commurity. Presently, the Young Adult Institute operates three-day treatment programs located in Manhattan, Brooklyn and Bedford Village in Westchester County. Collectively these programs offer a 35 hour-a-week program to well over 350 clients.

These programs operate at a high level of performance, and have earned the acclaim of many state and city officials who regularly visit the facilities. We have accepted the most challenging and difficult clients, and have shown that with client, family and staff determination and dedication, these individuals can maximize their full potential and become active, involved community members. Years ago many of these clients were turned away by other facilities and warehoused in large institutions. Today, with professional intervention and a dedicated staff to assist them, these individuals have made a remarkable adjustment to community living where they have been provided with the opportunity to achieve their fullest potential in the least restrictive environment.

BEST COPY AVAILABLE

THE EVENING ADJUSTMENT CENTER PROGRAMS

At the Young Adult Institute's evening adjustment centers, the emphasis is on providing further learning experiences to prepare the clients for living and working in the community. The Adjustment Centers provide the bridge to the world of work and adult responsibilities. Their socialization approach provides assistance in the transition to greater independence in sheltered or competitive employment. Members participate in group sessions which teach social and employment skills, emphasize communication techniques, and provide personal counseling. Liaison with nearly 100 academic institutions in the New York metropolitan area is maintained as part of our intern training program, enabling us to participate in the upgrading of training materials and equipment to keep abreast of new approaches and techniques in skill development, group work and vocational training. This activity has included affiliations and associations with Columbia, Fordham, New York University; Hunter College, City College, Manhattan Community College and Adelphi University, to name a few.

Additional special programs assist our evening adjustment clients in developing decision-making skills, enjoying arts and crafts, mastering more satisfying and successful behavior patterns, and improving their self-image. The program also includes extensive family counseling designed to improve relationships and understanding between client and family.

THE COMMUNITY RESIDENCES

Long before New York State mandated a policy of deinstitutionalization, community living was a reality for Young Adult Institute's clients. Today, we are the largest provider of community-based residential services for the mentally retarded and other developmentally disabled people in the New York metropolitan area. Perhaps more than any other aspect of our work, the community residences epitomize the Young Adult Institute's People in Partnership motif: people who care about people, giving freely of themselves and sensitive to each other's needs. The knowledge and experience we have accumulated from our comprehensive residential programs have helped erase many of the stereotypes associated with mentally retarded people, and we have been instrumental in allowing them to leave the institutions. We have also sought to avert the institutionalization of other develop-

YAI means learning to be self-sufficient

mentally disabled persons by teaching skills and offering programs which diminish the need for future institutionalization.

In keeping with our effort to serve the full range of mental retardation and development disabilities, we offer a full continuum of services--Intermediate Care Facilities for people with more extensive disabilities: Community Residences for our higher functioning residents: and Satellite Apartments for those who are in need of minimal supervision. Indeed, the significance of our Satellite Apartments program is that it constitutes a giant step forward in the normalization process. It provides our clients with the opportunity to assume primary responsibility for running their own apartments, hold competitive jobs and, in short, achieve their fullest potential.

Residence activities are carefully structured and staffed, and the emphasis is on expanding social skills and developing competence in daily living tasks. The focus is on cooking, shopping, home management, travel, the handling of money and other domestic skills. The emphasis in all the residences--those now in existence and those in the planning stage--is to provide self-reliance and personal dignity.

ALUMNI SUPPORT SERVICES

The Alumni Club of the Young Adult Institute serves many of the graduates of the evening adjustment programs and stress the therapeutic value of social contacts. Club activities are action oriented and cater to the special needs and interests of its members. This combines therapeutic recreation, milieu therapy and social clinical services. Club membership increased 25 percent in 1984.

YAI residents and Alumni at a recent outing

ADVOCACY

The struggle to ensure the rights of people with handicaps is an ongoing one. Consequently, YAI officials, led by Executive Director Joel M. Levy, testify at various governmental hearings to ensure that these rights are protected. YAI representatives have testified in favor of deinstitutionalization and in support of the right of mentally retarded and developmentally disabled people to live within the community in the least restrictive environment.

Recent activities have included testimony before the Senate Committee on Mental Hygiene and Addiction Control: testimony before U.S. District Court Judge Jack B. Weinstein regarding the Suffolk Developmental Court Case; major testimony at the hearings on the developmental disabilities system sponsored by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD); testimony at the hearings entitled "The Tragedy of Aging-Out: A Failure of Human Rights?" sponsored by the New York State Assembly Subcommittee on Human Rights (under the chairmanship of Assemblyman Steven Sanders); and testimony before the New York State Senate Select Committee on the Disabled (chaired by Senator John E. Flynn).

SELF ADVOCACY— YAI Counselor and Client testifying at hearings on developmental disabilities chaired by Arthur Y. Webb (right), Commissioner of New York State's Office of Mental Retardation and Developmental Disabilities (OMRDD)

YAI is determined to continue to fight for a greater share of residential beds for community clients; for decent and humane programs and services for mentally retarded citizens; for the implementation of family support services which would recognize the needs of parents and siblings and which keep families together rather than set them apart; and for laws and regulations which would prevent the degradation and dehumanization of innocent human beings. We firmly believe that the rights of every individual must be protected.

YAI is fully cognizant of the importance of spreading our message and maintaining a high level of public awareness of and support for our programs and services. Providing public education and developing positive attitudes toward people with disabilities are essential elements in achieving public acceptance of mentally retarded and developmentally disabled individuals. With this in mind, YAI representatives have appeared on numerous television and radio programs to keep the public informed. Indeed, YAI has emerged as the agency to which the news media turns for information regarding the "aging out" ("aging out" occurs when a mentally retarded or developmentally disabled person reaches the age of 21, and is no longer eligible for residential, educational and other child services provided by the State) crisis, the residential and clinical needs of clients, and other critical issues. YAI will continue to take advantage of every opportunity to inform the public about the importance of community-based programs and the need to safeguard the rights of mentally retarded and developmentally disabled people.

PROFESSIONAL ACTIVITIES

In addition to providing direct care to and advocating for the rights of mentally retarded and developmentally disabled individuals, the Young Adult Institute is also a highly renowned professional organiztion, nationally recognized for the excellence of our programs and conferences. Indeed, two of our most recent conferences, "From the 60's Into the 80's: An International Assessment of Attitudes and Services for the Developmentally Disabled" and "Normalization: A Redefinition in the Context of Reality," were cosponsored by the United Nations and by the President's Committee on Mental Retardation, respectively. Each of these conferences attracted an audience of approximately 2,000 people. Our 1984 national conference, "Critical Issues in Community Care for the Underserved," explored the special needs of mentally retarded and developmentally disabled people--especially those who are dually diagnosed, multiply handicapped, autistic, offenders, members of minority groups, and elderly and mentally disabled--who are too often neglected and ignored. Believing as we do that the families of mentally retarded and developmentally disabled people are also seriously underserved by the existing system of service delivery, the Conference also addressed the desperate need for family support services such as family counseling, crisis intervention, respite, in-home and out-of-home training, as well as informational services.

YAI has also recently inaugurated a Distinguished Lecture Series, "Choices and Challenges: Decision Points

New York State's Lt. Governor Alfred B. DelBello speaking at YAI Conference. Sitting (from left to right) are Connie McAlear, from the federal government's Office of Developmental Disabilities; Commissioner Eugene Aronowitz, Westchester County Department of Community Mental Health; Joel M. Levy; and Dr. Bert Pepper, Director, Rockland County Community Mental Health Center

KEEPING THE PUBLIC INFORMED—Joel M. Levy (center) meeting with reporters to discuss critical needs of mentally retarded and developmentally disabled people

for Professionals," which encompasses disciplines such as medicine, psychology, social work, special education and other related fields. Lectures in this Series--by addressing significant professional, programmatic, moral, legal and ethical issues affecting the human service fields--will seek to integrate new developments in the various fields, explore their relationships, and assess their impact on the field of mental retardation and developmental disabilities.

Our first Distinguished Lecture Series presentation, "Who Shall Live and Who Shall Die?" dealt with the sad and tragic case involving "Baby Jane Doe." The lecture presentation, which was made before a capacity audience at the McGraw-Hill auditorium and which was later featured in the New York Times, was designed to contribute to a better public understanding of the agonizing choices and decisions which confront parents, professionals, and policy makers.

Finally--in accordance with our professional commitment to disseminate knowledge about the mentally retarded and developmentally disabled, we have recently formed the YAI Press. This Press, which will publish the Proceedings of YAI's National Conferences and YAI's Distinguished Lecture Series, selected monographs dealing with timely and critical issues, a quarterly newsletter and other material, will be devoted to the promulgation of significant works and information dealing with social, ethical, fiscal and political issues affecting our profession.

NEW DIRECTIONS

YAI is constantly striving to improve our programs, to identify and meet gaps in services, and to anticipate new needs. What are some of these?

Family Support Services - Believing as we do that the families of mentally retarded and developmentally disabled people constitute an underserved population, YAI will continue to offer and fight for family support services such as respite, counseling, crisis intervention, and training.

Dually Diagnosed Clients - YAI has long been concerned with the plight of the dually diagnosed, individuals who are both mentally retarded and emotionally distrubed. The special needs of such people, and the types of services which they require, are presently being examined by YAI.

The Elderly - Another group which deserves greater attention than it has been given is the mentally retarded elderly. With more accurate medical diagnosis and treatment, this population has steadily grown. Unfortunately, however, the mentally retarded elderly remain one of the most neglected and ignored segments of society. YAI is deeply committed to remedying this situation. Indeed, some members of our staff are presently serving on a state-wide task force which was created for the sole purpose of ascertaining the needs of the elderly and devising programs which would meet their needs.

Quality programs don't just happen. They require painstaking planning, funding, implementation and hard work. We at YAI are proud of our vision, our commitment and our accomplishments. Working together--clients, parents, our board of directors, and the private and public sector--we shall continue to develop and provide the most innovative, most outstanding and most up-to-date programs available anywhere.

A Bequest or Contribution to the Young Adult Institute assures a continuum of services for the mentally retarded

The growth and development of YAI programs and services for the mentally retarded and developmentally disabled are made possible by the thoughtful and generous gifts of friends. YAI derives its strength, financial and otherwise, from such support, and your contributions, which are tax-deductible, are always welcome.

In addition to making a direct gift, many people plan ahead by earmarking funds, securities or other property for YAI through a Bequest or Deferred Gift.

The following form of Bequest is adequate for most purposes but should be checked with your attorney.

I give and bequeath to the Young Adult Institute, incorporated under the laws of the State of New York and located in the City of New York, the sum of $_____ (or other property), the same to be used for the general purpose of said organization.

The Young Adult Institute is a not-for-profit, nonsectarian organization providing a full range of counseling, training, treatment, and residential programs to mentally retarded and developmentally disabled people throughout New York City and Westchester County. YAI is committed to assisting these individuals in progressing from dependency and isolation to a more productive, self-sufficient and integrated role in society.